Exploring the application of self-monitoring of blood glucose results in insulin-treated diabetes: A case study of patients, their support persons and health care practitioners

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Thesis submitted for the degree of Doctor of Philosophy

November 2016

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ABSTRACT

Self-monitoring of blood glucose (SMBG) can be effective in preventing poor outcomes associated with diabetes mellitus but previous research has identified that SMBG is not being undertaken in line with current recommendations. Guidance informs health professionals to educate patients on how they should self-monitor but very little is know about how patients self-monitor in the real world. In this thesis, a quantitative scoping study is first presented. This study used routine data sources to examine the levels and patterns of self-montoring in different population groups and then proceeded to a larger qualitative study to explore and question what patients are doing in practice in relation to self-monitoring, and why. This involved a qualitative multi-case study of patients, their support people, health care practitioners (HCPs) and patient diaries. Ten individuals and their nominated support people and HCPs formed ten cases among whom 21 in-depth semi-structured interviews were carried out and six patient diaries analysed.

The exploratory work was framed around Stones' version of structuration theory and uncovered a complex linkage of individual motives for monitoring, associated responses and behaviours in relation to the motive, and the underpinning attitudes and beliefs behind the motive. The following key points emerged from the analysis. People have differing relationships with their diabetes and this links with the level of engagement they have with their condition. Resistance to support people and health services was commonly observed. Experiences of diabetes reviews were important, with an identified need for them to feel more like collaboration and less like surveillance. A significant factor was the gaps and limitations in knowledge and understanding around diabetes for patients, relatives, support people and HCPs; and, finally, there was a noted maintenance of blood glucose levels higher than recommended through SMBG in several participants, which stemmed from a fear of hypoglycemic episode.

The analysis concluded that although self-monitoring of blood glucose, in theory, and when considered in isolation, is a simple process to undertake, its

application in the wider context of self-management and the individual is much more complicated. The process is influenced by many complex factors and generates a variety of responses and behaviours, some not in keeping with good diabetes self-management. There was a significant lack of person-centered approaches to managing diabetes which was, in part, due to existing health systems and processes. Therefore, there is a need to raise awareness of the gaps that exist in terms of such approaches as well as the gaps in knowledge and understanding of individuals with diabetes and those caring for and supporting them. In more specific terms, it is essential to develop and evaluate individual approaches to patients in relation to their self-monitoring and associated self-management in the context of their own lives, which involves the assessment of engagement and understanding around self-monitoring.

KEY WORDS

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LIST OF ABBREVIATIONS

BNF	British National Formulary
CHI	Community Health Index Number
DAFNE	Dose Adjustment for Normal Eating
DESMOND:	Diabetes Education and Self-management for Ongoing and Newly Diagnosed
DH	Department of Health
DKA	Diabetes Ketoacidosis
FOH	fear of hypoglycemia
GRO	General Register Office
HbA1c	Glycated haemoglobin A1c
HCP	Health Care Practitioner
HIC	Health Informatics Centre
HONK	Hyperosmolar Hyperglycaemia Non-Ketotic coma
HYPO	Hypoglycaemia: when blood glucose levels drop too low and produces physical symptoms
IDDM	insulin-dependent diabetes
LOC	Locus of Control
MSLT	Modified Social Learning Theory
OGTT	oral glucose tolerance test
RCT	randomised controlled trial
SCI-DC	Scottish Care Information – Diabetes Collaboration
SIMD	Scottish Index of Multiple Deprivation
SMBG	Self-monitoring of blood glucose
SOPs	Standard Operating Procedures
WHO	World Health Organization

ACKNOWLEDGEMENTS

STATE OF ORIGINAL AUTHORSHIP

The work contained in this Thesis has not been previously submitted to meet requirements for awards at this or any other higher educational institution. To the best of my knowledge and belief, the Thesis contains no material previously published or written by another person, except where due reference is made.

Signature:

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CHAPTER 1: INTRODUCTION

Self-monitoring of blood glucose is a key component of self-management for people with diabetes, and how it is undertaken has an impact on their health outcomes. However, it is recognised that many individuals with diabetes are not undertaking self-monitoring as they should be, resulting in not self-managing the condition effectively. This in turn increases their risk of diabetes-related complications which can have an impact on their quality of life and life expectancy, as well as significantly increasing health service costs (St John et al. 2010).

Given the health costs at stake of poor diabetes self-management, including the personal costs of poorer quality of life and lower life expectancy, and the enormous health service costs, people with diabetes need to be assisted in undertaking self-monitoring correctly; but to do this we first need to understand the scale of the problem and why people with diabetes are not undertaking this process as they should. This thesis addresses these important questions through a scoping study within a health region in Scotland, and further to this an exploratory study that examines in depth why patients with diabetes self-monitor in the way they do, and assesses their associated self-management in the context of their lives and the structures around them, incorporating the perspectives of those closely connected to them and their self-management.

1.1   Background

1.1.1 Diabetes

Diabetes Mellitus is a collection of metabolic conditions which raise blood glucose levels persistently above normal ranges. Diabetes is estimated to affect around 366 million people globally with a predicted increase to 552 million by the year 2030 (Diabetes UK 2012; Dunstan et al. 2002). In Scotland, just over 237,000 members of the population are affected, with a range of 4% – 5.2% prevalence between health boards (Diabetes UK 2012). Diabetes Mellitus is a significant health issue with an ever-increasing prevalence, described as a global epidemic (Lee et al. 2010; Schnell et al. 2008). In 2014, the number of

people diagnosed with this condition in the UK was 3.2 million, the biggest increase in a single year since 2008 (Diabetes UK 2014). Diabetes is a complex chronic condition with 1.5 million deaths reported globally in 2012 as a direct cause and is now classified as the fifth most common cause of death in the world, with life expectancy reduced by up to 20 years depending on the type of diabetes (Department of Health 2001a; Klein and Klein 1998; Roglic et al. 2005; World Health Organization (WHO) 2014).

This metabolic condition affects insulin functioning and is characterised by hyperglycaemia alongside altered carbohydrate, fat and protein metabolism. Insulin is a hormone produced by the pancreas and regulates the amount of glucose in the blood. A lack of insulin prevents this necessary regulation taking place and, left untreated, glucose levels increase and thereafter can compromise the systems of the body (American Diabetes Association 2008).

Diabetes has been a classified condition for tens of centuries and, although now has an uncomplicated and simple identification and diagnosis process, in earlier times, and prior to understanding around glucose metabolism and the role of insulin, the manifestation of its symptoms mystified the medical community (Gutteridge 1999).

There are four clinical types of diabetes, all with differing aetiology. The most common are Type 1 and Type 2 diabetes:

Type 1: This type of diabetes results from destruction of the insulin-producing cells and is often the result of an immune-mediated disorder. As the pancreas is unable to produce enough insulin, those affected are dependent on exogenous insulin to maintain life. It affects approximately 11% of people with diabetes and most commonly occurs in childhood and was previously thought of as 'juvenile onset diabetes' or termed 'insulin-dependent diabetes' (IDDM) (Gutteridge 1999).

Type 2: This is the most common and affects approximately 88% of people with diabetes. Here the pancreas does not produce enough insulin for the body requirements, or the body is unable to utilise the insulin produced effectively due to a resistance to insulin action. Although this group may not require

insulin to maintain life, insulin might be integrated into treatment plans in an aim to improve glycaemic control (American Diabetes Association 2008; Scottish Diabetes Survey Monitoring Group 2014; WHO 2006). Lifestyle factors are noted to be influential in the development of this condition with a demonstrated link between this type of diabetes and obesity. Although previously thought of as a disease of adulthood, with increasing levels of obesity across all population groups, type 2 diabetes is now being diagnosed in adolescence and even in those of younger ages in some minority groups (Klingensmith et al. 2016).

There is a group of conditions which account for only one-to-two percent of diabetes. These are less common and are diverse disorders which cause or are associated with hyperglycemia. These include: genetic defects of insulin-producing cells and insulin action, diseases of the pancreas, disorders of the endocrine system, drug-induced anomalies, infections, and immune disorders. Other specific types of diabetes are caused by other factors, including genetic conditions and gestational diabetes (Gutteridge 1999; WHO 2006).

Diabetes is classed as a chronic disease/condition, also known as a long-term condition. Essentially, this means that it is a condition which can be controlled with medical intervention but there can be no cure or return to 'normal' (Department of Health 2004). The diagnosis of chronic conditions such as diabetes can be life-changing for the individual. Patients report feelings of fear due to the enormity of the condition and its implications which involve a need to make significant lifestyle changes along with regular interaction with health care practitioners (HCPs), including: General Practitioners, diabetic nurses, dieticians, diabetologists and practice/community nurses (Bhatnagar 2009). Diagnosis is confirmed by: fasting blood glucose equal to or greater than 7.0 mml/L, the presence of symptoms of diabetes with a confirmed non-fasting blood glucose equal to or greater than 11.1 mmol/L, or an oral glucose tolerance test (OGTT) with a confirmed blood glucose after two hours of equal to or greater than 11.1 mmol/L (Gutteridge 1999).

Due to the chronic nature of this condition, diabetes requires continuous medical care which includes multifactorial risk-reduction strategies, including

intensive clinical and behavioural intervention and care to self-manage the condition. In addition to the direct mortality reported globally, there are further indirect health effects associated with diabetes, affecting quality of life, which are often associated with poor self-management. Management plans are aimed at achieving and maintaining blood glucose levels as close to normal as possible, thereby reducing the risk of diabetic-related complications (both acute and long-term), and in turn increasing life expectancy. Diabetic complications are extremely debilitating, decrease quality of life and reduce life expectancy (Glasgow et al. 2002; The DCCT Research Group 1988).

Complications of diabetes can be both short-term (acute), or long-term (chronic):

Short-term complications

Diabetes Ketoacidosis (DKA) and Hyperosmolar Hyperglycaemia Non-Ketotic coma (HONK): both are life-threatening acute conditions requiring emergency medical treatments.

Hypoglycaemia: a more common complication which can be self-treated but if left un-managed can lead to unconsciousness requiring emergency medical treatment.

Long-term complications

Classified as:

- Macrovascular complications (affecting large vessels): heart disease (myocardial infarction being the most common cause of death in patients with diabetes), stroke, and peripheral vascular disease, which can lead to amputations.
- Microvascular complications (affecting small vessels): renal disease and nephropathy, which can lead to end stage kidney failure and require dialysis, retinopathy, and neuropathy (Diabetes UK 2012; Scottish Diabetes Survey Monitoring Group 2014; Rizvi and Sanders 2006; Saudek et al. 2006).

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1.1.2 Management of Diabetes

The primary aim in the management of diabetes is to maintain blood glucose levels within a normal range. The main rationale for this is the close connection between stable glycemic control and the reduced risk of diabetes-related complications. Achievement of such stable glycemic control can consequently improve quality of life through lowered health care needs and, ultimately, extend life expectancy (St John et al. 2010).

The goal of restoring the 24-hour glucose profile as close to normal as possible can be achieved by providing patients with the necessary information and equipment to self-monitor their blood glucose and comply with medication and diet regime. This can vary from diet only, diet and oral medication, or injectable insulin therapy.

Insulin therapy is used principally for type 1 patients and for type 2 patients who are unable to achieve close to normal glycaemic levels with oral medication and diet.

Insulin is prescribed and administered in many forms, ranging from long-acting, rapid-acting and continuous infusions, with glycaemic control most effectively achieved when insulin doses are adjusted according to the patient's control (Rosenthal et al. 2011). Insulin is usually self-administered by subcutaneous injection or via an infusion pump (Campbell and Lebovitz 2001).

Oral medication is used in patients with type 2 diabetes. There are a range of oral preparations available which have various classes of actions, specifically: improving insulin sensitivity, triggering insulin production, and altering the rate at which complex carbohydrates are digested and absorbed within the gastrointestinal tract (Campbell and Lebovitz 2001).

Diet and Lifestyle: Management also requires the balance of diet and lifestyle factors, including physical activity and stress (Campbell and Lebovitz 2001).

Diabetes is managed by and often shared between a team of health professionals within specialist services and community and primary care,

depending on the type of diabetes and how it is treated (Evans and Scrivens 2015).

1.1.3 Normal Parameters

Recommended blood glucose target levels are detailed below:

- A fasting plasma glucose level of 5 – 7mmol/litre on waking, and
- A plasma glucose level of 4 – 7mmol/litre before meals at other times of the day,
- After meals, 5 – 9mmol/litre at least 90 minutes after eating, and under 8.5mmol/litre for type 2 patients (NICE NG17, 2015; NICE NG28, 2015).

1.1.4 Self-management

With the increase in prevalence of chronic conditions, the term 'self-management' is now a frequently used terminology when describing how patients self-administer treatment, monitor and supervise their chronic condition with the goal of achieving health and wellness, and this often includes health promotion and health behavioural concepts. The term considers the patient as an active participant in the overall management of their condition and, for those with chronic conditions, this will be a 'life-long task'.

 Many factors can influence how a patient can and will self-manage their condition and this in turn can have a significant impact upon health outcomes in relation to their disease (Lorig and Holman 2003). Self-management requires that the individual has the necessary knowledge and skills to allow them to undertake the necessary requirements of self-management. A wide variety of interventions are used in an attempt to arm patients who are required to self-manage their condition with the appropriate knowledge and skills. The most successful approaches to diabetes self-management are noted to be broad-spectrum approaches which are patient-directed, include ongoing education, physician collaboration, and are supportive in nature (Renders et al. 2000).

1.1.5 Self-care

Although the term 'self-care' is sometimes used synonymously with self-management, it should be noted that self-care does have a different meaning as it is more focused on managing health than managing disease.

The WHO defines self-care as: "the ability of individuals, families and communities to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a health-care provider." (WHO 2009).

1.1.6 Self-management of Diabetes

Some fifty years ago, diabetes was treated in hospital and primarily managed by one specialist doctor. Through time and an ever-increasing prevalence, this management has been disseminated to primary and community health professionals and now involves a significant degree of self-management by the patient themselves (Evans and Scrivens 2015).

Self-management in diabetes, sometimes termed as 'diabetes self-care', is a process which requires the development of knowledge and skills to allow the individual to maintain health and to function in the context of their own life. The specific knowledge and skills requirements relate to the balance of dietary intake, physical activity self-monitoring of blood glucose, as well as the calculation of and self-administration of medication. This balance can be a complex process and requires good health literacy skills alongside problem solving.

How a patient self-manages their condition and the effect of their self-management on glycemic control should be overseen/managed by a health care professional who should guide the patient in a manner that empowers them in their self-management efforts (Shrivastava et al. 2013).

In response to the number of people self-managing chronic conditions, health services are implementing policy in relation to self-management: to empower individuals to be partners in their conditions, to build capacity to support self-

management, improve services, and upskill health service staff to support patients to self-manage their condition (Scottish Government 2009).

1.1.7 Self-efficacy

This concept refers to an individual's ability to use their skills and understanding to manage their health management and behaviour. Many factors have been noted to affect self-efficacy, such as personal judgement of worth, self-esteem and self-assessment, how they are perceived by others, and beliefs and attitudes (Naidoo and Wills 2016).

1.1.8 Monitoring of Diabetes

Glycated haemoglobin A1c (HbA1c): is an accurate retrospective glycaemic assessment undertaken by health services and deemed to be the most reliable method of testing metabolic control. It assesses glucose levels over a period of time (3–4 months), therefore demonstrating the effect of diet, exercise and treatments over this time frame. The aim is for these results to be used by HCPs, in conjunction with the patient, to assist with self-management planning (Boutati and Raptis 2009; Hill-Briggs et al. 2006). HbA1c can also be used to estimate the risk of diabetic complications (Hill-Briggs et al. 2006), with target levels of 48 – 58 mmol/mol (Diabetes UK 2012; Rosenthal et al. 2011).

Self-monitoring of Blood Glucose (SMBG): A key part of diabetes self-management is to self-monitor blood glucose. This provides real-time information of control which can allow individuals to make key safety, dietary and treatment decisions. SMBG has been shown to improve clinical outcomes in terms of regular estimations of risk.

SMBG is a process of blood testing involving a finger prick of blood from the diabetic patient onto a testing strip which converts and reads the current glucose level with the aid of a monitoring device (Hill-Briggs et al. 2006). This method of testing was introduced post-1970, around the same time as HbA1c testing was developed (Boutati and Raptis 2009; Clarke and Foster 2012). At this time, the focus of diabetes management began to move from the doctor's office to patient involvement and self-management within patients' own homes

(Saudek et al. 2006). The sophistication of testing devices has progressed rapidly over the decades with today's testing meters now more user-friendly, allowing SMBG to be undertaken quickly and easily (Spollett 2010).

There is strong evidence linking attention to SMBG with improved glycemic control in insulin users (Murata et al. 2003; Naik and Ellis 2008; Sarwat et al. 2010; Skeie et al. 2009; St John et al. 2010). There is also research which suggests an association between SMBG and improved health outcomes for patients with diabetes through life expectancy and the reduction of diabetes-related complications, specifically studies showing that frequent self-monitoring improved the stability of HbA1c, which is known to decrease diabetes-related complications (Huang et al. 2012; Schneider et al. 2007; Weber et al. 2010).

The advantages of this recommended glycaemic monitoring tool are its ability to be used anywhere and at any time (Bhatnagar 2009) and the provision of a 'real-time' picture of blood glucose levels, compared to HbA1c, which is retrospective, as well as providing information regarding control at various times throughout the day, including before and after meals (Boutati and Raptis 2009). Through the observations of 'real-time' glycaemic levels over periods of time, clinicians and patients are informed regarding medication levels, diet and activity management, which can in turn assist with metabolic control (Chubb et al. 2011; Clarke and Foster 2012; Kirk and Stegner 2010; Yeaw et al. 2012).

SMBG has been shown to be key in preventing poor outcomes among patients with diabetes who are treated with insulin (Montagnana et al. 2009) and, on the basis of this, guidance has been developed to inform patients through HCPs on recommended SMBG practices. Current guidance recommends routine self-monitoring in type 1 diabetes, around 4 times daily, with frequency and timing adapted to individual patient requirements. Guidance for type 2 diabetes suggests that routine testing should be undertaken only in those treated with insulin and for HCPs to evaluate 'temporal patterns' so that treatment can be appropriately adjusted (Hansen et al. 2009; Nomura 2002; SIGN 2010).

Therefore, although HbA1c provides an estimation of the glycaemic levels over time which can predict risk, glycaemic levels can fluctuate significantly

throughout the day and it has been suggested that it may be the actual day-to-day movement from normal glycaemic level (not always evident in HbA1c readings) which is the actual predictor of risk (Rose and Kitchell 2003).

Over recent years, as technology has advanced, health-related computer and internet-based programs now include applications which can assist diabetic patients with SMBG through logging and managing results, providing education and networking with others within diabetic communities (Wake and Cunningham 2013).

1.1.9 Diabetes education

As noted previously, diabetes self-management is a complex process which requires the application of knowledge and skills to effective problem solving. For this reason it is imperative that patients are provided with the necessary information and skills, through educational processes, to allow them to undertake self-monitoring and apply this to their self-management effectively.

Many educational programmes are available for patients with diabetes, addressing different types of diabetes and different needs. The two most common courses currently available in Scotland are:

DAFNE: Dose Adjustment for Normal Eating, provides patients with type 1 diabetes with the skills necessary to estimate the carbohydrate in each meal and inject the correct dose of insulin (DAFNE 2016).

DESMOND: Diabetes Education and Self-management for Ongoing and Newly Diagnosed. This is a collection of self-management education modules, toolkits and care pathways for people with type 2 diabetes (DESMOND 2008).

1.1.10 Local Policy

Government support for self-management emerged in the late 1990s and progressed to the recommendation of upstream changes in the Wanless report, which vouched for a culture of sharing responsibility for health and well-being (Wanless 2002). This move towards patient choice and involvement in their condition was first outlined in a keynote report: 'The expert patient: a new

approach to chronic disease management for the 21st century' (Department of Health 2001b).

An important part of diabetes self-management is that education forms part of many interventions. These interventions are influenced and initiated in response to policy around diabetes care and management. Diabetes is one of the conditions of focus for service frameworks, strategies and action plans; in Scotland, for example, the Scottish Diabetes Framework (NHS Scotland 2002).

The key driver of self-management in the UK has been the Expert Patient Program. This stemmed from the 'Expert Task Force' formed in 2001, which recommended that self-management programmes for chronic diseases would be effective in terms of encouraging independence, with improved health outcomes for patients and reduce health service cost and demand (Donaldson 2003; Secretary of State for Health 2001).

This was followed by the release of 'Six Years On: Delivering the Diabetes National Service Framework Report', which has set national standards of care for people with diabetes, identifying areas requiring improvement in future years (Department of Health 2010).

In Scotland, the Scottish Diabetes Group is a national steering group formed in 2002, tasked with taking forward the implementation of the Scottish Diabetes Framework and Action Plan. Their aim is to promote collaboration, peer support and best practice across Scotland (NHS Scotland 2002). This group oversees the review and ongoing development of the national diabetes strategy.

1.2 Purpose of the Study

Diabetes Mellitus has been identified as a major health issue which has an impact on health services as well as on the individual's quality of life and life expectancy, mainly through risks associated with the condition that are associated with how an individual self-manages their condition. It has been identified that effective self-management can improve metabolic control and therefore in turn improve clinical outcomes. A key component in the self-

management of diabetes is SMBG, by allowing individuals to monitor their blood glucose and adjust their management in relation to this. The use of research in health care has the potential to significantly influence the effect of interventions aimed at assisting patients and families in the management of diabetes. Although self-management has been an area of interest for policy makers and researchers alike, there is very little research in individual self-management or self-management in the real world (Hinder and Greenhalgh 2012).

Previous research has shown that individuals with diabetes may not be self-monitoring as often as recommended (Evans et al. 1999). More up to date information is now required to describe the current state of this problem.

In addition to this, given the aforementioned lack of research exploring aspects of self-management, including SMBG in the individual and in the real world, it is imperative that we explore the practical application of SMBG in individuals going about their everyday lives, in order to understand the factors contributing to individuals testing their blood glucose, or not testing as the case may be, and, more importantly, why those specific factors are significant. By understanding why individuals behave in certain ways we have the potential to change and influence practices and behaviours.

1.3   Aims of the Study

The aims of the research presented in this thesis were to:

1) Describe the extent of the problem and compare this across population groups
2) elicit the perceptions of those involved in SMBG;
3) analyse the perceptions in relation to theories around self-management of chronic diseases;
4) apply a well-defined theoretical framework to analysis and demonstration of findings; and
5) draw some theoretical and practical implications for SMBG practices.

1.4   Structure of thesis

This thesis is organised into eight chapters. The first chapter sets down the context of the study with background information and briefly outlines the research design and structure of the thesis. Chapter 2, the literature review, begins with a discussion of the review process, followed by critiques of relevant evidence and protocol around SMBG: the clinical effectiveness and financial implications of SMBG; patterns of self-monitoring in other areas; the wider benefits of SMBG; patient experiences and barriers to testing; and problem solving with test results. The literature search process is outlined and the rationale for this type of review is described, followed by the review itself.

Chapter 3 provides statistical information over the past ten years of how often patients with diabetes (type 1 and insulin-treated type 2) test their blood glucose through secondary data analysis with comparison across population groups. The rationale for the first phase of data analysis work is provided, followed by the research design, population and sample, ethical considerations, results, tables and discussion, along with a published article relating to the findings (Appendix 1).

Within Chapter 4, the research questions for the case study are presented, followed by the study design and methodology as well as the ethical and practical considerations. A theoretical framework has been used to organise and frame the results. An explanation of this theory and the rationale for its use is discussed. Results are presented along with the different stages of analysis. The discussion is presented in five sections with an explanation of their linkage.

Chapter 5 outlines the methodology and methods.

The results and the progression of the analysis are presented in Chapter 6.A discussion of the final analysis from the case study forms chapter 7 and is organised into five discussion themes. The final section of the discussion addresses the strengths and weaknesses of this study.

The final Chapter forms the conclusion of all sequential parts of this study. It revisits the model and considers the strengths and limitations of the research and the implications of the findings for practice and future research.

1.5   Summary

This chapter has provided background information relating to diabetes; the condition, its prevalence, its impact on health and how it is treated and managed. An overview of self-management has been provided along with the importance of SMBG in the management process. The purpose and aims of the study have been outlined, along with an overview of the structure of the thesis.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter constitutes a literature review which covers the broad areas of knowledge around SMBG that have informed this study.

The review has been organised around 3 areas:

1. Self-monitoring in practice and the rationale for testing
   - Clinical effectiveness of SMBG
   - Patterns of self-monitoring
   - Patient experiences; benefits and barriers to testing
   - Problem solving results of SMBG;

2. Clinical guidance and the burden of diabetes; and

3. Self-management theories.

SMBG is recognised as being effective and is recommended as routine practice in the management of patients with type 1 diabetes. For those patients with type 2 diabetes, the literature is less clear: guidance does recommend routine testing for those treated with insulin, although there is conflicting evidence regarding the benefits of testing and the timing and frequency of testing in those patients treated with diet or oral medication (SIGN 2010). Evaluation of reviews, trials and meta-analyses regarding testing in non-insulin-treated diabetic patients report that this process, with its cost implications and possible adverse psychological effects, has minimal effects on glycaemic control (Evans et al. 2013a; Evans et al. 2013b). In fact, there have been suggestions that SMBG in the non-insulin-dependent group can result in poorer quality of life, impeding self-care, reduction of self-efficacy and increasing health cost without any clinical benefit (Chubb et al. 2011; Fisher et al. 2012; Polonsky et al. 2011a). Routine testing is therefore not recommended within this group, except for those at increased risk of hypoglycaemia, those experiencing acute illness, those undergoing significant changes in pharmacotherapy or fasting, those with unstable or poor glycaemic control, and those who are pregnant or planning a

pregnancy. It should, however, be noted that there are varying views and understandings of the guidance in relation to SMBG, particularly around timing and the recommendations for those with type 2 diabetes (Kirk and Stegner 2010; Kjome et al. 2010a; Montagnana et al. 2009; SIGN 2010).

This literature review will focus on patient groups for whom current evidence and guidelines recommend routine testing; patients with type 1 diabetes and patients with type 2 diabetes who are treated with insulin. However, some of the literature reports on SMBG in both insulin-using and non-insulin-using patients with type 2 diabetes, and therefore there may be some reference to this group if relevant within the review.

A systematic and staged approach has been taken to review of the literature, which at the outset focused on self-monitoring in practice and the rationale for testing.

The overall aim of the literature review was to identify all literature/research relating to SMBG in insulin-treated diabetes to determine how often individuals are testing, how are they testing, what makes them test, what they are doing with their results in terms of self-management and what influences self-monitoring.

2.2 Self-monitoring in practice and rationale for testing

This self-monitoring review used the search terms: 'Blood glucose monitoring', 'Diabetes Mellitus' and 'Insulin', and accessed the following databases: the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Health Source, and MedLine, from November 2002 – November 2012. The search included papers published over a ten-year period to ensure the currency of the literature appraised. Papers were excluded from the initial search manually if they focused on: patients who have non-insulin-treated type 2 diabetes, gestational diabetes, continuous glucose monitoring, paediatrics, and adolescents, as detailed below. The reason children were not included was due to the parental influence on self-managing practices for children. In addition, diabetes in pregnancy and gestational diabetes were also excluded,

as pregnancy is a time when behaviours tend to change from the norm due to the motivation of neonatal and maternal well-being (Anderson 2001).

Figure 1: Literature search flow chart

The initial search was repeated monthly, using alerts to identify new publications. Publications previous to the 10-year time frame were included if deemed important to the search area.

To ensure key papers were not missed, each of the article references were checked to ensure familiarisation with key authors in this area.

Literature was critiqued using Caldwell's 2005 framework. This model offers areas which apply to both qualitative and quantitative research and provides guidelines for each area (Caldwell and Henshaw 2005).

The review identified, and was then subsequently organised around, the following themes:

Clinical Effectiveness of SMBG: This includes the role SMBG plays in glycaemic control, the effect of glycaemic control on risk of diabetic complications, the relationship between SMBG and glycaemic control, and the financial cost and cost savings of SMBG.

Patterns of self-monitoring: This includes the number of patients practising SMBG and the frequency of SMBG within patient population groups, a comparison between practices in SMBG with current recommendations, and also the relationship between SMBG frequency and glycemic control.

Other benefits of SMBG: This includes all reported benefits other than clinical outcomes, for example, improved emotional health and self-efficacy.

Patient experiences of SMBG and barriers to SMBG: This explores the patient perspective, patient feelings regarding SMBG, barriers to SMBG, and patient relationships with the HCP in relation to SMBG.

Results, approaches, pattern recognition and the use of new technology: This includes what patients do with results and the actions they take, in terms of: the level of structure to SMBG processes; the education provided; and how this affects what patients are actually doing with self-monitoring through observing the monitoring of patterns over time. This area also addresses the use of new technology and how it is used and integrated into health services.

These themes emerged from the basis of initial reading. It should be noted that some papers address more than one of the subject points and thus appear in more than one section.

2.2.1 Clinical Effectiveness of SMBG

Although in theory SMBG appears to be crucial in managing diabetes over time, providing a scientific evidence base for the practice has proved difficult, and although it has been identified as important in self-managing diabetes, its role in demonstrating control is not fully clear (Kolb et al. 2010; Sarwat et al. 2010). This section addresses: firstly, the role of SMBG in glycemic control; and secondly, how glycemic control can reduce the risk of diabetic-related complications and then links SMBG to this potential reduction in risk; concluding with an assessment of the financial cost of SMBG as well as the financial cost of reducing diabetic-related risk.

A recent systematic review undertaken by Breland et al. (2013) sought to identify the relationship between SMBG and glycemic control in type 2 diabetes (insulin- and non-insulin-treated). Data from this review suggest that SMBG may assist glycemic control but the author identified a need to understand when, how and who this may affect and calls for more exploratory approaches to allow practical application of future findings (Breland et al. 2013).

When considering the effect of SMBG on glycemic control, this has been determined through related HbA1c levels. Improved HbA1c levels have been noted in patients with type 1 diabetes who self-monitor (Evans et al. 1999; Skeie et al. 2009). Findings from a randomised controlled trial (RCT) of 159 type 1 patients with diabetes noted improvement in HbA1c levels that were more significant when SMBG was practised in a structured manner (Skeie et al. 2009). Structured SMBG will be explored in more detail and its significance in relation to glycaemic control in section 2.2.2. Research reporting on the link between SMBG and improved control in patients with type 2 diabetes has been less conclusive, particularly in those not treated with insulin. St John et al.'s (2010) review and meta-analysis reported on an improvement in HbA1c in non-insulin-treated diabetes. In contrast, Evans et al. (2013b) found no evident association between SMBG and glycemic control in this patient group. A review of recently published evidence and a systematic review of five RCTs of individuals with type 2 diabetes treated with insulin have demonstrated a stronger link between improved glycemic control with SMBG in this patient

group, supporting the value of frequent monitoring (Naik and Ellis 2008; Sarwat et al. 2010).

Recent investigation now suggests that HbA1c may not be an accurate enough measure, that it is the day-to-day fluctuations from normal, not always seen in HbA1c, which are the real predictors of risk (Rose and Kitchell 2003). This emphasises the importance of encouraging and supporting effective SMBG practices for those individuals for whom it is recommended.

Studies have identified difficulties in establishing the influences of SMBG on associated control. For example, Zgibor and Simmons' (2002) survey of a New Zealand multi-ethnic community noted higher levels of monitoring in patients (type 1 and 2) with raised HbA1c levels. These authors noted that this did not suggest that better control is associated with less monitoring. Rather, these particular patients may be aware of their unstable control and hence are aiming (or being advised by HCPs) to make improvements through SMBG (Zgibor and Simmons 2002).

The importance of maintaining glycemic control is to reduce the risk of diabetic-related complications. It has been suggested that poor control at certain times of the day can increase diabetic-related risk factors, for example, postprandial hyperglycemia, which is a reported risk factor for cardiovascular disease (O'Kane and Pickup 2009). Chubb et al.'s (2011) study of type 2 diabetic patients considered this concept when seeking to identify how SMBG correlates with HbA1c and fasting glucose. This cross-sectional study calculated the patient's highest and lowest pre- and post-prandial glucose result. Here the mean SMBG result correlated closely with the HbA1c and the mean pre-prandial result correlated with the fasting glucose level, thus demonstrating that SMBG values, if interpreted and used effectively, can predict prevailing glycaemia (Chubb et al. 2011). Pursuing this further, Zhang et al.'s (2012) RCT of patients with type 2 diabetes sought to identify how post-prandial SMBG affects other health-related indicators in addition to glycemic control, measuring lipids, weight and cardiovascular events over a six-month period. Results demonstrated improved glycemic control, serum lipids and weight loss in patients who had reached their target HbA1c when they practised post-prandial

SMBG two times daily. In addition, lipids, weight and lifestyle habits were noted to improve (Zhang et al. 2012). Such evidence emphasises the importance, in relation to reducing cardiovascular risk, of practising SMBG at specific times which are relative to meal times throughout the day. This indicates the need for patients and HCPs to consider glycemic patterns in diabetes management.

Experimental trials, such as the Diabetes Control and Complications Trial and the UK Prospective Diabetes study, identified that maintaining stringent glycaemic control, of which SMBG is part of the process, considerably reduces risks of long-term diabetic complications in patients with type 1 and insulin-treated type 2 diabetes (Hortensius et al. 2012a; Schütt et al. 2006). It is also known that regular attendance at clinics and adhering to self-management plans can improve outcomes in diabetes through providing education and support for patients in the practice of SMBG (Bhatnagar 2009).

Although the majority of research has concentrated on the short-term effects of self-monitoring in terms of glycemic control, Tengblad et al.'s (2007) Swedish study observed self-monitoring effectiveness on glycemic control in relation to preventing long-term complications in type 2 diabetes. This cross-sectional study noted no association between SMBG and glycemic control in individuals with insulin-treated diabetes as well as no association between diabetic complications in those who self-monitored and those who did not, raising the question as to what patients are doing with their results (Tengblad et al. 2007). It should also be noted that the cross-sectional design of this study does not allow for clarity as to which variable influenced the other. The impact of SMBG in patients with type 2 diabetes on non-fatal (MI and Stroke) and fatal episodes, had not been researched prior to a German epidemiological study called the ROSSO study which studied patients with type 2 diabetes over time periods to determine health outcomes. The findings of this study suggested that those most likely to practise SMBG were poorly controlled diabetic patients. These patients subsequently intensified their diabetic treatment and therefore experienced a reduction in non-fatal and fatal events (Schneider et al. 2007). However, it has been suggested that such studies, measuring health outcomes in relation to SMBG, may provide slightly misguided findings. This was

demonstrated when Hoffman and Andersohn (2011) tested the ROSSO study for design flaws and concluded that the protective effect of SMBG on all-cause mortality fails to account for a time of exposure. Within this study, those included in the self-monitoring cohort had to remain alive for a least 1 year to meet the inclusion criteria and could therefore have been a healthier group. Subsequently this excluded from the self-monitoring cohort those who died within this time period and assumes these individuals did not self-monitor. Therefore results are biased in favour of those who remained in the self-monitoring cohort due to design of the observational time period, a term known as 'immortal time bias' (Hoffmann and Andersohn 2010). Similarly, a community-based Australian evaluation on the prediction of outcomes from self-monitoring in patients with type 2 diabetes, assessed diabetes-related morbidity, cardiac death and all-cause mortality. The initial findings demonstrated a marked association between SMBG in individuals with both insulin- and non-insulin-using type 2 diabetes and a reduced risk of adverse health outcomes. However, following modification in relation to possible explanatory variables, the study concluded that SMBG on its own is unconnected with reduced mortality in both treatment groups of type 2 diabetes patients (Davis et al. 2007).

In addition to difficulties demonstrating long-term reduction in health-related risk and mortality from SMBG, there has been little improvement in glycemic control over time noted in diabetic patient groups, despite all the evidence regarding the effect of SMBG on glycaemic control. This lack of an evidence base has led to uncertainty around the exact role of SMBG in improving clinical outcomes, and, in times of poorly resourced health services, concerns have also been raised regarding the financial costs of SMBG for health services and its cost effectiveness (Meetoo et al. 2011).

The cost of SMBG represents a sizeable portion of diabetic prescribing spending and, over the years, this has increased significantly (Sanyal et al. 2008). There are reports of GPs wasting money on home glucose monitoring equipment for type 2 patients, with accusations that they are prescribing 'willy nilly' (Gough 2003, p. 12). A Canadian evaluation of 'real-world' usage and

cost (in relation to the cost of diabetic treatment) for insulin-using type 1 and type 2 diabetes patients over a one-year period calculated that 40% of the diabetes-related pharmaceutical costs were attributed to SMBG (Yeaw et al. 2012). A financial analysis of self-monitoring has also suggested that, in some patient groups, current levels of SMBG exceed guidelines. Moreover, if SMBG was taking place in line with current guidance (especially the non-insulin-treated diabetic patients), a potential annual saving of 17 million pounds could be made (Belsey et al. 2009), which could be utilised to investigate evidence-based interventions aimed at improving glycaemic control and specifically addressing the steps between SMBG and modification of management (Davis et al. 2007).

Although SMBG has been deemed by some to be a costly process, when considering its potential to encourage and facilitate glycaemic control and the role in early prevention of diabetic-related complications, it could be argued that SMBG is imperative to subsequent health cost savings and, as described in Schnell et al.'s (2008) economic analysis, "value for money" (Schnell et al. 2008). Several studies have analysed the cost of undertaking SMBG compared to the direct costs of diabetic-related complications, all concluding that SMBG has the potential to provide significant savings in relation to the health costs associated with such complications (Neeser and Weber 2009; Palmer et al. 2006; Weber et al. 2010). However, it should be noted that pharmaceutical companies funded some studies. Yeaw et al. (2012) emphasise the need to also evaluate other diabetic-related costs, for example; laboratory and radiology tests and inpatient care episodes, as well as diabetic-related complications (Yeaw et al. 2012).

In summary, there is some evidence that SMBG is associated with improved glycaemic control in type 1 and type 2 diabetic patients treated with insulin, and such control can reduce the risk of diabetic-related complications, which has the potential to provide health services with significant cost savings. Specifically, certain times of the day are important for SMBG in predicting glycaemia through the identification of patterns. However, positive health outcomes related to SMBG have been noted only in the short term, with little clear evidence of an association between SMGB and reduced risk of diabetic-

related complications or mortality. It has been suggested that this may be due to SMBG being merely a tool for managing the condition and outcomes are more dependent on the interpretation of the results and consequent action taken (Kolb et al. 2010). This indicates a need to fully understand the exact role SMBG plays in outcomes, through large-scale, long-term follow-up studies (Bhatnagar 2009; Boutati and Raptis 2009; Karter et al. 2006; Welschen et al. 2005).

2.2.2 Patterns of self-monitoring

Although it is recognised that SMBG has a part to play in maintaining glycaemic control for individuals with insulin-treated diabetes, there are mixed views regarding testing timing and frequency, with guidance reported to be vague (Saudek et al. 2006). This section will address the numbers of patients who practise SMBG and the frequency of SMBG, particularly comparing population groups and relating these levels to current guidance. This will be followed by consideration of how frequency is related to glycemic control and possible influences of the frequency of testing.

Frequency of testing, the numbers of those testing and differences within specific groups has been evaluated over recent years, identifying a general increase in testing over this time, with Evans et al.'s (2012) Tayside study, using routinely collected data, identifying an increase from 15.5% in 1993 to 29.8% in 2009 in the proportion of individuals with type 2 diabetes who received reagent strips. As noted in other studies, testing is generally more prevalent in females than males, in middle-aged groups, those of a higher education level and those who are more recently diagnosed with diabetes and less prevalent in those living in more deprived areas. However, it should be noted that studies using routinely collected data have less investigator control and can be subject to incompleteness and measurement error (Evans et al. 2012; Kjome et al. 2010b; Secnik et al. 2007; Jaworska et al. 2004; Pan et al. 2007; Hansen et al. 2009). Educational level is not measured and known in all of the aforementioned studies and, where this has not been calculated, other measures were used to identify socioeconomic status; for example, Evans et al.'s (2012) Scottish study uses the Scottish Index of Multiple Deprivation

(SIMD). This is a proxy measure of socio-economic status by using the postal code to identify areas of deprivation. Limitations to this measure exist, and it can be a very blunt instrument. For example, people living in deprived areas may not always be disadvantaged and vice versa, and deprivation is also more difficult to calculate in rural areas. Therefore, although this measure does to some extent tap into variables in relation to socio-economic status, we cannot be sure how accurate this is.

Similarly, a 2004 UK cohort study sought to identify current practice of SMBG within three general practices in Aberdeen. This study noted that SMBG occurred most commonly in those treated with insulin, but there were limited actions taken in relation to the results. This study calls for a more in-depth exploration of patient feelings and views regarding SMBG as well as the views of health professionals (Stewart et al. 2004).

Previous reviews have also noted racial/ethnic disparities in testing, suggesting lower frequency of SMBG within all diabetic patients from minority groups (Adams et al. 2003; Kirk et al. 2007). Compliance with SMBG within ethnic groups has been noted to increase following the implementation of self-management programmes demonstrating the potential to address inequalities. However, a further decline in the level of testing has been noted over time, emphasising the need for further research to explore interventions which will encourage long-term adherence to self-management through SMBG (Mah et al. 2006). This observed lower frequency of testing in minority low-income populations has also been liked to other factors, for example, those with psychosocial issues, those living where there is less support available from HCPs or families, those with anxieties regarding the condition, and those reporting pain while undertaking the procedure (Levine et al. 2009).

We know that current guidance suggests routine testing for all type 1 diabetic patients (approximately 4 times daily) and for those type 2 patients who are treated with insulin (frequency dependent on treatment, control and individual circumstances) (SIGN 2010). However, a large number of these patients do not test as frequently as recommended (Evans et al. 1999; Fisher et al. 2011), with only around half of this patient group testing daily (Hansen et al. 2009;

Kjome et al. 2010b) and, conversely, 1% using more than 10 strips daily (Kjome et al. 2010b). In contrast, a Nova Scotia study calculating strips, again, using routinely collected data, demonstrated that patients receiving strips were generally testing as frequently as recommended, with only small proportions over-testing or under-testing (Sanyal et al. 2008). Many studies have reported large variance in testing frequency and it has been suggested that this may be due to HCP views on SMBG, confusion around guidance, and inconsistent advice regarding SMBG. In response to this, there has been a call for clearer definitive guidance, particularly in relation to structured SMBG.

Structured SMBG is an approach where testing is undertaken within a defined regime, including interpretations and associated management and also allows collaboration between patient and HCP (Polonsky et al. 2011b). However, when considering large variations in practice of SMBG, patient motivation for diabetes self-care should also be considered as an important contributory factor (Polonsky et al. 2011b).

These findings have led researchers to question what influences the frequency of SMBG. An African-American cross-sectional population-based study suggested that medication regime and healthcare provider recommendations to test were significant independent predictors of more frequent SMBG, illustrating the importance of HCP input. This was noted particularly within vulnerable groups, and the authors recommend future educational interventions that include HCP collaboration with patients and assistance with the interpretation of results and associated adjustment of diet, activity and treatment (Skelly et al. 2005). The design of this study provides a snapshot in time of such influences and it is therefore difficult to determine whether outcomes have been effected or caused by other agents/factors and also whether this has international significance.

When considering testing frequency and associated glycemic control, studies have noted some improved control in relation to more frequent self-monitoring in the type 1 diabetic patient group, but such improvements are less clear in the type 2 group (Evans et al. 1999; Jaworska et al. 2004; Lecomteet al. 2008). Murata et al.'s (2009) observational study examined type 2 diabetic patients

who, at the outset, were non-insulin-treated. These patients were then categorised at the end of the two-year study to identify those who required insulin initiation, specifically examining how the SMBG frequency was associated with HbA1c levels. Results demonstrated that glycaemic control was associated inversely with SMBG in stable diabetic patients as well as those requiring intensive treatment modification; again suggesting the potential benefits of SMBG, particularly in those patients who are pre-insulin-treated (Murata et al. 2009). Similarly, Laguna et al.'s (2013) prospective cohort study of mainly poorly controlled diabetic patients suggested that insulin-treated patients who practised a high level of self-monitoring demonstrated a relative improvement in glycaemic control (Laguna et al. 2013). In addition, Huang et al.'s 2012 Taiwanese observation of the relationship between frequency of SMBG and fluctuation in HbA1c demonstrated that more frequent SMBG was associated with improved blood glucose stability and decreased the fluctuating HbA1c level, thereby reducing diabetic-related complications (Huang et al. 2012).

Farmer et al. (2008) sought to move beyond studies looking at patterns of monitoring through prescribing databases and undertook a cross-sectional survey of diabetic patients collecting strip prescriptions from community pharmacies in the UK, in an aim to provide additional data. Findings identified an increased level of SMBG in insulin-using diabetic patients and noted that insulin-treated patients experienced more episodes of hypoglycaemia than other treatment groups. Increased SMBG was also linked to more frequent episodes of hypoglycemia across all treatment groups, raising the question as to whether episodes of hypoglycemia are fully understood by diabetic patients (Farmer et al. 2008).

Continuing this theme, Karter et al.'s (2006) U.S. longitudinal four-year study assessed the differences in new SMBG users against ongoing users in relation to the relationship between frequency of testing and glycaemic control. The results demonstrated a reduction in HbA1c with new SMBG patients regardless of treatment. However, changes in SMBG frequency of ongoing users was linked to an inverse graded change in A1c in pharmacologically treated patients

only; thus reinforcing that long-term benefits are noted only in those patients with diabetes who are pharmacologically treated. It should be noted, however, that this study did not address differing levels of education provided to patients regarding their self-management (Karter et al. 2006). Morgan et al.'s 2010 longitudinal study sought to identify the effects of SMBG on glycemic control in type 2 diabetic patients and noted a reduction in HbA1c in those who self-monitor frequently, therefore suggesting that self-monitoring is most effective in maintaining good glycemic control when undertaken frequently. This was a longitudinal study which can more accurately identify the order of variables, although this particular study was over a significantly short one-year time period, which may have been too short a time frame to note change (Morgan et al. 2010). A German cross-sectional study also noted that frequency of testing was associated with better control in type 1 patients and insulin-treated type 2 patients only, this association being more evident in patients on more intensive insulin regimes (Schütt et al. 2006).

In conclusion, improved control has been noted in relation to how frequently patients carry out SMBG, principally for those patients recommended by clinical guidelines to test regularly. The numbers of patients carrying out SMBG and frequency of testing has generally increased over time. However, those who are recommended to self-monitor are generally not testing as regularly as recommended, with some not testing at all, and a small proportion are over-testing. In addition, there is variability in testing between population groups and the challenge is to alter self-monitoring behaviour of diabetic patients with greater health risks. This finding is of particular importance as these happen to be the groups identified as those who test most infrequently; the elderly, minority groups, and low socioeconomic groups (Adams et al. 2003). It should be noted that there are limitations to some of the studies reviewed in this section, for example: self-reported data, routinely collected data, and small study samples, which have been noted above. There is a need for future research to define SMBG more accurately in terms of the whole process rather than just the 'finger prick' and determine whether patients are being non-compliant or whether they do not fully understand SMBG, as well a need to promote closer monitoring of patients who are undertaking SMBG in practice.

2.2.3 Other Benefits of SMBG

The most obvious benefit of SMBG is its provision of immediate patient feedback of glycaemic control, therefore reinforcing the need for lifestyle modification and aiding the correction of hypoglycaemia (O'Kane and Pickup 2009). However, the level of testing has not always noted an association with improved control, particularly in those patients not treated with insulin (Lecomte et al. 2008).

Over recent years, diabetes-related studies have explored how SMBG can affect quality of life and it has been suggested that improved quality of life may be gained through patient empowerment and self-efficacy (O'Kane and Pickup 2009). Conversely, SMBG has also been linked with depressive-type symptoms (Chubb et al. 2011; Fisher et al. 2012; Polonsky et al. 2011b). Fisher et al. (2011) investigated whether a structured SMBG protocol could affect depression and diabetes-related distress, and the results demonstrated a marked reduction in depressive symptoms and disease-related distress within the group who received the structured SMBG, particularly where there was collaboration between the patient and physician regarding medication and lifestyle changes. This improvement occurred regardless of improvements in glycaemic control. Therefore, contrary to some reports of the adverse emotional effects of SMBG, when combined with a structured programme, improvements in emotional health are noted (Fisher et al. 2011). So, is it the collaboration or structure or both which aids emotional health? Clearly, further exploration of the process is required to understand this phenomenon.

Thus, if undertaken in a structured manner and with appropriate education, SMBG can improve quality of life through patient empowerment, which can in turn improve self-efficacy, a noted facilitator of positive health behaviour. It has been suggested that future studies need to look at specific subgroups of diabetic patients and identify where self-monitoring may be more beneficial (O'Kane and Pickup 2009).

2.2.4 Patient Experiences of SMBG and Barriers to SMBG

This section explores the patient perspective on SMBG, their thoughts and feelings, and the relationship with their HCP (in the context of SMBG), as well as perceived barriers to self-monitoring.

Patient perspectives have been identified as being important when considering approaches to SMBG and avoiding negative patient perceptions of the process. However, literature in this field is scarce (Fisher et al. 2012; Hortensius et al. 2012b). Although devices are now more sophisticated and easy to operate, there are differences in how patients approach SMBG and therefore we need to examine the process from the patient perspective, taking into account contributing factors including social and psychological factors (Spollett 2010; Wagner et al. 2005).

Snoek et al. (2008) sought to address social and psychological factors through the lens of a biopsychosocial model developed by the authors. Firstly, this model addressed the actual decision to test, how the finger prick is perceived, and then overcoming barriers through recognition of psychological barriers, that is to say, motivation to self-monitor. The importance of understanding how patients perceive the benefits and barriers to self-monitoring was identified, prior to addressing them (Snoek et al. 2008). Continuing this theme, a recent Portuguese cross-sectional survey of type 2 diabetes considered partner involvement in relation to social-cognitive variables about SMBG (intentions, attitudes, subjective norms, perceived behaviour control, action planning and coping planning), and their association with adherence as well as glycaemic control in type 2 individuals of a one-year diagnosis. The results identified that positive partner support aided the intention to self-monitor and was a clear predictor of adherence to SMBG, emphasising the important role that partners can play in self-care (Costa et al. 2012).

Findings from a qualitative Norwegian study looking at perspectives of type 1 diabetic patients and insulin-using type 2 diabetic patients in relation to SMBG, found that patients can perceive health professionals as being focused on tight glycaemic control but patients struggle between this and quality of life, resulting

in performing SMBG to their own perceptions and personal goals (Hortensius et al. 2012b). The author develops this theory around a model that interprets the data, and recommends developing and validating a clinical measuring tool of patients' perspectives of SMBG (Hortensius et al. 2012b).

Peel et al. (2007) explored the views of patients with type 2 diabetes about SMBG over a four-year period of time in Lothian, Scotland. Results identified that those patients reporting well-controlled blood glucose levels viewed SMBG positively, but those reporting poor glycaemic control demonstrated reservations about SMBG. Specifically, three themes emerged within the results of this study: firstly; 'the role of the HCP' was identified as being crucial in relation to how SMBG was viewed. It was felt that doctors focused on HbA1c results and appeared disinterested in SMBG results, thereby giving the impression that it was not worth undertaking self-monitoring. The second theme was 'interpreting readings and management of high readings'; some deemed the readings to be an indication of how good or how bad their management had been. Women appeared to report this self-blame more than men. And thirdly, the ongoing role of SMBG; this was noted to decrease over time and has been termed "monitoring fatigue" (Peel et al. 2007 p. 493). As alluded to in other research, SMBG readings are reported by some as being difficult to understand, especially in relation to why there are fluctuations in readings and subsequent actions required following testing (Peel et al. 2007). This study is noted to be limited in objectivity as it relied on patient accounts with no measurement of glycemic control.

Davis et al. (2006) also identified the importance of partners of type 2 diabetic patients in self-monitoring behaviour in their 'Freemantle Study', which examined the association between SMBG and improved control, with findings from this study noting that patients in a stable relationship were more likely to monitor. Although this large community-based study included all treatment groups, only 12% were insulin-treated, thus affecting the statistical power of results by not providing a large enough sample of the population of interest; those recommended to test regularly. This five-year longitudinal study did not explore the process of SMBG interpretation to actions taken in relation to

results and associated glycemic control, and calls for long-term studies analysing the steps between SMBG and modification in management (Davis et al. 2006).

A theoretical model has also been used by Nadkarni et al. (2011) in an observational study in a Michigan health district, which examined the determinants of SMBG. This model focused on two concepts; making the decision, and enacting the decision. The model assumes that if a person has a desire to achieve a goal, this will proceed to a goal intention (the desire being the pre-requisite to intention in providing motivation). This model also takes into account three decision-making features: importance, effort and confidence as the motivational variables, in addition to the consideration of other associated variables. The results identified that, following a goal intention, the individual moves to considering specific goal-associated behaviours to allow goal achievement. In brief, through providing insight into how strategies or plans can assist patients to identify means of achieving their goals, individual plans can be formulated which may be more effective than a standardised approach (Nadkarni et al. 2011).

 A previous cross-sectional survey of US veterans also considered patients' perceptions, through self-assessments of diabetic patients regarding their diabetic management and how this can affect glycaemic control (Heisler et al. 2003). Specifically, this study examined the associations between patients' assessments of their self-management, HbA1c levels and the subsequent diabetic care they received. The results identified that those rating their self-management high demonstrated lower HbA1c levels and received a higher level of diabetic services than those rating self-management at a lower level. These authors pose a question for future research; why those who report better self-care have access to more diabetic services (Heisler et al. 2003).

Barriers have been identified as important considerations in relation to adherence, such as financial cost of testing, inconvenience, poor understanding of SMBG, the actions required following testing, and discomfort from the procedure (Hortensius et al. 2012b; Naik and Ellis 2008). People with diabetes have reported finding SMBG tiresome and unnecessary and for this reason

undertake it in an ad hoc manner (Fisher et al. 2012). Nyomba et al. (2002) sought to identify, through a longitudinal single-blinded study, whether cost is a barrier to testing. In this study, a group of patients were provided with testing strips at no cost, whereas the control group were given a small amount of strips and asked to purchase further strips when needed. Both groups reported similar barriers to testing at the end of the two-year period, with 'inconvenience' rated highest. HbA1c levels decreased in both groups initially; however, these levels progressively increased through time in the control group. Therefore, although inconvenience was identified as a major barrier, cost was also clearly an issue (Nyomba et al. 2002). Similarly, Zgibor and Simmons' (2002) study of barriers to SMBG showed there was a significant link between personal finance and lower levels of SMBG, regardless of age, sex or ethnicity. Conversely, Ruelas et al.'s (2009) prospective observational study of adherence and control within a low-income Latino community identified that even when medication is provided free, low-income groups still have difficulties adhering to treatment regimes, and these authors call for future studies to look at psychosocial factors and access to health food as possible barriers to effective self-management (Ruelas et al. 2009). Invasiveness of the procedure was identified as a significant barrier in Wagner et al.'s (2005) survey.

In addition, some see SMGB as a "report card that signifies when they have failed to closely follow their diabetes care plan" (Spollett 2010, p. 127). So, instead of encouraging self-care, in some cases SMBG is viewed as a barrier (Spollett 2010).

As previously noted, diabetes-related distress has been linked with diabetes and can have implications on an individual's ability to self-manage. Lloyd et al.'s 2010 study of patients with type 1 diabetes demonstrated a relationship between depressive symptomology and diabetes-related distress, regardless of variables such as gender and age of onset. In particular, physical activity was noted to positively affect the depression scores and the subsequent ability to self-manage. The authors highlight the importance of individualised management plans with a view to overcoming diabetes distress and to encourage self-care (Lloyd et al. 2010).

Behaviour change has also been identified as being important in overcoming barriers to self-monitoring. Al-Khawaldeh et al.'s (2012) cross-sectional study explored the influences on diabetes management behaviour through structured patient interviews and medical notes analysis in an aim to identify how self-efficacy can play a part in influencing behaviours. Here the most frequently performed behaviours were medication taking and dietary adherence and the most infrequent were SMBG, exercise and foot care. In addition, dietary self-efficacy and dietary self-management resulted in better glycaemic control. Self-efficacy was generally low, but of those with increased self-efficacy there was reported enhanced diet, exercise, self-management, SMBG and medication administration behaviours. The authors suggest that the reason for patients not adhering to recommended self-monitoring and associated management may be down to: lack of knowledge, skills confidence and motivation, that is, self-efficacy. This study called for future programmes to include educational and motivational interventions and also points out that education in isolation may not be sufficient and should be combined with motivational tools and followed up with educational refreshers (Al-Khawaldeh et al. 2012). Fisher et al. (2013) implemented a brief-intervention motivational interviewing technique used to influence lifestyle factors within primary care, which focused on patients with difficulties adhering to self-care. The results demonstrate that such an intervention can be effective in the encouragement of SMBG, although significant resource is required to implement such interventions and individual assessment could identify those who would benefit most (Fisher et al. 2013). A review by Hirsch et al. (2008) suggests that behaviour change interventions for SMBG should be implemented within current systems and resources, and also advocates for professional development and education around goal setting to assist with this (Hirsch et al. 2008).

In brief, it is important to explore SMBG from the patient perspective, considering social and psychological factors as well as the biological factors. Barriers require further exploration and ways to overcome issues, particularly in relation to individual needs and the needs of minority groups (Zgibor and Simmons 2002).

Existing research has briefly addressed this area but has called for further exploration, particularly in partner involvement and the HCP role in the process, the certain characteristics in patients which make SMBG and glycemic control difficult, as well as how patients are applying results, strategies, tools and interventions that assist with this, how patients perceive self-care, and how to overcome barriers. There is a call for future studies to compare those who have partner support with those who do not, situations where SMBG can cause anxiety and depression, and to explore education programmes that consider patients' perspectives and include partners (Clar et al. 2010; Costa et al. 2012; Peel et al. 2007). The difficulties of studying the effects of SMBG on patients who are managing a complex condition with many affecting factors and treatments in the context of their own lifestyle regimes has been acknowledged (O'Kane and Pickup 2009).

2.2.5 Results, approaches, pattern recognition and the use of new technology

There is little empirical evidence to tell us about the process of self-monitoring of blood glucose, from testing to actions taken and what advice patients are being given regarding the required actions to take following SMBG. It has been suggested that this may be due to SMBG being merely a tool for managing the condition and that outcomes may be more dependent on how results are interpreted and acted upon by patients as well as how this compares to what is being advised and recommended by HCPs (Kempf et al. 2010; Polonsky et al. 2011a).

Although there are many studies that have examined glycaemic control as the key outcome in relation to SMBG, there is limited research regarding diabetes self-management behaviour as a reported outcome in relation to SMBG (Kerr et al. 2011; Wang et al. 2012). Furthermore, there is a lack of evidence around the use of SMBG results, differences within specific patient groups, and what this really means (Kerr et al. 2011). It has been reported that many patients do no actually act on the results of SMBG; in fact, many individuals with diabetes are carefully checking and recording their blood glucose and taking no action on the basis of results (Fisher et al. 2012; Heller 2007; Peel et al. 2007; Stewart

et al. 2004). A Polish cross-sectional study observed the link between SMBG and associated self-management behaviour and suggested that the key determining factors were a lack of understanding of the condition and of the aims of management (Jaworska et al. 2004). Polonsky et al.'s (2011a) study surveyed type 2 diabetes patients (insulin- and non-insulin-treated) attending a one-day conference and noted that more than half of the sample reported not acting on SMBG levels which lie outwith the normal range and, additionally, often not taking these results along to clinic visits (Polonsky et al. 2011a). This convenience sample of patients attending a conference may not accurately reflect the views of all patients, as, generally, individuals attending such events are likely to be more motivated regarding the management of their condition. Therefore, the number of patients not acting on results may be higher than that reported in this research.

Moreover, a recent study by Wang et al. (2012), emphasised that it is not just actions taken but 'problem solving' that is key to diabetic management through SMBG. Wang et al. (2012) explored problem solving (not just actions taken) in relation to SMBG and discovered that increased problem solving was noted in those patients who undertook SMBG in a structured manner (Wang et al. 2012). The results of this study identified that although patients reported self-monitoring at least once daily, the majority did not problem solve effectively in response to high and low readings. Frequency of testing has also been related to problem solving in diabetes self-management and increased problem solving has been noted in those patients testing more frequently (Wang et al. 2012). There is very little empirical evidence and very few rigorous studies to tell us what advice diabetic patients are receiving in relation to frequency of testing as well as the actions to be taken after obtaining results (Karter 2006; Polonsky et al. 2011a).

This review of the literature within this study relating to approaches to SMBG has identified that there appears to be many approaches to performing SMBG (Hortensius et al. 2012b), indeed, with some patients approaching it in an unstructured manner (Fisher et al. 2012). The question of what the HCP advocates has been addressed in section 2.2.2, however, when considering

HCP approaches, Abbot et al. (2007) explored community nurses' practice around SMBG. This small study reported that although recent guidance suggests otherwise, the community nurses who were interviewed believed that there was reliable evidence to support advocating SMBG in all diabetic patients. Results suggested that advising on SMBG had become a routine task which forms part of the community nurse's diabetic management duties, possibly replacing important patient engagement and education. In addition, the findings suggested that, while they did practice SMBG, patients could not and did not then apply their results to self-care. The authors did point out that although nurses need to provide evidence-based practice, the dissemination of evidence around SMBG should not be the sole responsibility of the nurse, but instead, that this should be achieved jointly with other health care services (Abbott et al. 2007).

Collaboration has been identified as an important factor in diabetes self-management, for which SMBG is a key aspect. Rosenthal et al.'s (2011) RCT evaluated the effort required to maintain normal HbA1c levels in insulin-treated type 2 diabetes in an elderly population. Data were analysed for adjustments made over a period of time by measuring the intensity and frequency required. The results reported that several adjustments were required over this time period which utilised various components of insulin. These results emphasise the considerable effort necessary by the individual to manage their diabetes to a glycemic-stable level and how involved and complicated this process can be. With this in mind, this research calls for future interventions which will facilitate a collaborative approach between patients and their HCP or to provide patients with the necessary skills and confidence to manage these adjustments safely and independently (Rosenthal et al. 2011). A recent cluster randomised trial by Fisher et al. (2012) reported that patients achieved better control with structure, active medication and lifestyle modification where there was joint collaboration between patient and GP. Polonsky et al.'s (2011b) survey also identified that sharing the results of SMBG with HCPs can improve management plans and glycaemic control (Polonsky et al. 2011b). It has been suggested that this may be due to the fostering of a sense of engagement in their diabetes which may consequently increase self-efficacy and autonomous motivation (Fisher et al.

2012). A similar outcome was noted in Chen et al.'s (2008) RCT, concluding that SMBG should not be viewed on its own but instead as an intervention which can be effective if undertaken in conjunction with structured education and HCP engagement and oversight (Chen et al. 2008). These authors determined that this was down to the combination of a systematic approach along with the motivation of education in achieving better self-management and therefore improved control.

A more structured and intensive approach to practising SMBG has been identified as a possible key to improved self-management, and many studies have explored structured approaches. Improvements have been noted with this approach in terms of improved metabolic control and patient empowerment (Franciosi et al. 2001; Kolb et al. 2010; Murata et al. 2003; Skeie et al. 2009).

Franciosi et al.'s (2001) self-reported survey also identified that SMBG can enhance metabolic control if it is part of a structured educational program tailored to self-management (Franciosi et al. 2001). Kolb et al.'s 2010 review also noted similar positive outcomes when SMBG was undertaken in conjunction with intensive structured treatment therapy and education. These authors also identify the need for structured programmes which empower patients to self-manage their condition and the importance of early intervention with SMBG skills following diagnosis, thus implying that early education and combined management programmes should be commenced as soon as possible following diabetes diagnosis (Kolb et al. 2010). Structured programmes have been deemed too costly to implement by some. However, an Iranian cost analysis of an intensive management program, which included education and structured SMBG, demonstrated marked improvements in HbA1c, as well as cost savings in relation to complications and mortality which outweighed the cost of the intervention program (Aghili et al. 2012). In addition, it has also been noted that tools used to evaluate structured SMBG programmes have continued to be used by clinicians following completion of the study, with demonstrated improved understanding and involvement from patients and the achievement of the sustainability of a structured programme (Friedman et al. 2013).

SMBG has been reported to be effective in the control of blood glucose levels if it is combined with an educational component, particularly in those patients who demonstrate poor glycaemic control, in a review assessing the effectiveness of SMBG in the management of type 2 diabetes (Szymborska-Kajanek et al. 2009). In particular, standardised education has been identified as assisting with motivation to SMBG. Education to date has often involved the technical aspect of performing SMBG and instructions for when to self-monitor, while lacking continuation or follow-up. Education should follow a step-by-step, building up of expertise and knowledge. Spollet's (2010) review calls for research to be undertaken to identify the most effective method of education and outlines some key education concepts: determining monitoring times, individualised monitoring times, related action to results, follow-up after education and the review of logs to assess patient understanding of results and patterns (Spollett 2010).

However, it has been identified that there is a need to consider the literacy required to fully understand and manage diabetes, a concept termed 'health literacy', of which numeracy is an important element. Osborn et al.'s (2009) cross-sectional study examined how this understanding affected the individual's ability to self-manage their diabetes in African-American culture. Their results demonstrated that it was diabetes-related numeracy (and not African-American culture) that considerably affected glycemic control. These authors suggest that by identifying those at risk of low diabetes numeracy skills, dedicated educational interventions could be implemented. They also call for future studies to test such programmes (Osborn et al. 2009).

We know that patients do not always adhere to the recommended guidance on SMBG, but it is not clear precisely what HCP are recommending. Hortensius et al. (2012a) sought to approach this subject from the HCP perspective, to investigate what they are recommending to insulin-treated diabetic patients around SMBG. This cross-sectional survey in the Netherlands noted that, in general, there was significant variation in the recommendations given by HCPs. The authors suggests that this may be due to either previous professional

experience, or lack of knowledge around clinical guidance for SMBG (Hortensius et al. 2012a).

Continuing this idea, it has been identified that training needs, for both the patient and HCP, in relation to SMBG are not always addressed, specifically in relation to the action taken following SMBG (Kerr et al. 2011; Montagnana et al. 2009; Bhatnagar 2009). There is a call for SMBG education to be ongoing and individualised to patient need, and to include the difference between SMBG and HbA1c results as well as their relationship. In addition, there is a need for clear and consistent guidance from HCPs on when to monitor, how to interpret and action results, and for patient understanding to be assessed with consideration of literacy (Osborn et al. 2009).

Recent reviews have recommended that HCPs evaluate temporal patterns when advising patients on timing a frequency of testing, so that medication can be adjusted appropriately (Nomura 2002). Specifically, SMBG provides important and more detailed information than HbA1c, particularly regarding times of day, which has the potential to identify key times of importance in maintaining glycemic control (Meetoo et al. 2011; Parkin and Davidson 2009). A study by Sarwat et al. (2010) examined the relationship between SMBG and HbA1c using five randomised clinical trials. Results reported individual SMBG levels were not as significant as multiple values, therefore reinforcing the need to monitor regularly throughout the day and examine patterns, thus allowing assessment of overall glycemic control (Sarwat et al. 2010).

A review by Kerr et al. (2011), addressing the value of SMBG in relation to actions taken, questions whether new technology could be developed to assist patients to make appropriate decisions and actions following testing (Kerr et al. 2011). As technology is advancing and the internet is accessed widely within all communities (Wake and Cunningham, 2013), there is now an awareness of how information technology can potentially assist with diabetic management and, in turn, outcomes and intervention studies have identified the potential to integrate new technology into health systems to effectively manage diabetic patients (Kaufman 2011; Lee et al. 2010). There is now a wide range of new technology to assist with diabetic management in the form of mobile phone and

tablet applications with features including blood glucose recording which provide trend analysis, medication recording with alerts , physical activity monitors, diet regulators, and insulin calculators, some with community links, for example, the 'IBG Star', which is inserted directly into the iPhone and blood results are instantly displayed (Tran et al. 2012; Wake and Cunningham 2013). Although data management tools for mobile phones have been identified as being much easier for people to manage than previous labour-intensive log books, a large number of patients continue to use paper-based methods (Skrøvseth et al. 2012). Moreover, those who are using technology to log and manage their diabetes are not sharing or involving the HCP, which is a missed opportunity for collaboration and health service integration in technical management (Wake and Cunningham 2013). Furthermore, mobile phone interventions for the self-management of diabetes have been demonstrated to reduce HbA1c levels, regardless of patient characteristics or the type of mobile phone intervention (Liang et al. 2011).

It has been suggested in an NHS report on how to engage patients to manage their own health conditions that this new technology is in its infancy and not currently widely disseminated within health services (Coulter 2006). There are a wide range of apps from free ones to those that are more expensive and all vary, therefore there is a need to consider the most appropriate to the individual (Tran et al. 2012). It has been suggested that such technology may not be available to all population groups as low socioeconomic status has been associated with a slightly lower access to technology. Still, 92% of the lower wage earners use the internet, with most of the population now computer literate (Wake and Cunningham, 2013).

When analysing self-monitoring results, it is not the regular recording of blood sugar levels that is key, but rather, it is the analysis to identify patterns and cues to patients' lifestyles that can allow for necessary adjustment. If patients can identify patterns, they are able to make changes prior to the body being exposed to damage during prolonged periods of raised glucose level. This concept has been termed 'Pattern Management' or 'Pattern Recognition'. Pattern Management is the systematic identification and application of blood

glucose results by the patient in conjunction with the HCP in their ongoing diabetic management (Linekin 2002). Although this has been undertaken for many years in the clinical setting, only now have we developed an understanding of how this approach may assist in achieving better clinical outcomes for the management and predicting of patterns that lead to unwanted situations (Parkin and Davidson 2009; Skrøvseth et al. 2012). Pattern management depends on the patient's and HCP's ability to understand glycaemic control, how to recognise patterns in glycemic levels, and how to act on these patterns (Bhatnagar 2009). Identifying relevant clinical patterns can provide patients with diabetes with a meaningful understanding of the relevant parameters to their condition, therefore offering a platform for management and discussion with their HCP (Skrøvseth et al. 2012).

Rao (2013) has undertaken a review and observations via survey of software and apps that are designed to assist with diabetic control, information sharing and associated assistance with managing diabetes. Results reported that data management tools to assist with logging self-monitoring information can be helpful in managing the condition and some apps were noted to be much easier for people to manage than previous labour-intensive log books (Rao 2013). A recent observational study which explored how SMBG information can be used in pattern management with new technology applications found that all applications tested required significant training for the patients, although once training was provided and patients were able to visualise their results, they were then motivated to make improvements through management and undertake further monitoring (Skrøvseth et al. 2012). It has been suggested that the use of such technology and pattern management requires a strong partnership with the HCP and within the context of the family and wider community, as well as individualised ongoing education. The potential of such systems has been identified as an innovative way for HCPs to support patients living in more remote geographical areas and larger number of patients (Kaufman 2011; Linekin 2002).

As with technology for patients to use themselves to log and manage their diabetes, technology for HCPs to analyse results has also advanced over

recent years and numerous types of software have been developed to track diabetic information (Vashist et al. 2011). However, health systems have been slow to recognise the potential benefits of utilising such technology mentioned above, particularly for chronic disease management such as diabetes. While there are numerous independent online diabetes communities, mobile apps, websites and networking opportunities, these have yet to be integrated into health care systems. Regulation of such applications has also been identified as an important factor to ensure patients are not exposed to inconsistent information which may not have an evidence base (Melnik 2011).

Kerr et al. (2011) call for future research to test technology innovations that support treatment algorithms, new models of care, and testing recommendations, to develop actionable devices and associated material and then test them against current and continuous systems (Kerr et al. 2011). In response to such calls, Spanakis et al. (2012) undertook a study across Europe which implemented a health management system for diabetes care called the 'REACTION' project. This study aimed to develop a platform to incorporate a range of services to support patient diabetes monitoring and feedback and, ultimately, diabetic management through the implementation of new care models that incorporate new technology. This included a glucose management system that monitored blood glucose as well as dietary intake. A range of views were obtained from patients, HCPs, social scientists and support persons which identified that the use of technology assisted with regaining autonomy, although the cost of integration in health services must be considered. Privacy and confidentiality is an important factor when patient information is being transmitted via new technology and the consideration of other variables are important, for example, emotion, psychological stress, exercise and variability of lifestyle (Spanakis et al. 2012).

In conclusion, many diabetic patients are testing their blood glucose levels but not acting upon the results and, more importantly, not 'problem solving' in terms of interpreting results and comprehending the meaning of the result and actions required in relation to the reading (Evans et al. 2013b). Future research needs to look at the process of SMBG from the finger prick to interpretation and

associated actions along the way as well as motivation. Patients need to be integral to their management if they are going to achieve close to normal glucose levels and thereby reduce the risk of diabetic-related complications. Again, HCP involvement and collaboration has been identified as being important in the 'problem solving' process and for encouraging a structured approach to SMBG with goal setting to maintain glycemic control. In addition, education and training needs for the patient and HCP should be considered, particularly in relation to pattern recognition, the rationale around actions taken, current recommendations and the use of new technology. HCPs need to assess regularly the patient's ability and understanding around interpreting and acting on results of testing (Naik and Ellis 2008). Future research is needed on the most effective ways to provide education and feedback and to match these to various types of patients (Clar et al. 2010).

There is a potential for more effective management through the understanding, identification and application patterns within SMBG, as well as an awareness of new technology systems which may be able to assist with such pattern recognition and associated management. In addition, such management would allow services to reach those who are disadvantaged by limited access to services, and those who are too busy, not keen or unable for various reasons to attend clinics. The biggest challenge is linking this new technology with complex health systems which are often fragmented, lacking resource and hampered by concerns regarding security (Hirsch et al. 2008; Melnik 2011; Wake and Cunningham 2013). Further research is required to explore how this technology can be integrated into health services.

Additional areas which did not emerge from the search criteria but were identified as being important to informing research in the area of self-monitoring are noted below.

2.3 Clinical Guidance

The key National Clinical Guidance on SMBG include: the National Institute for Clinical Excellence (NICE), and the Scottish Intercollegiate Guidelines Network (SIGN). The most recent guidance from both guidelines are NICE 2015 and SIGN 2010 (updated in 2013) and are referred to throughout this thesis. As

noted earlier in this thesis, guidance recommends regular testing approximately four times daily in type 1 diabetes and in insulin-treated type 2 diabetes. As well as addressing SMBG, these guides cover all aspects of diabetes management.

2.4 Self-management theories

Alongside the literature review above, the literature around self-management theories was also consulted. Health behaviour theories have been identified as being important when considering patient self-management and therefore have been applied to diabetes self-management research and the development of interventions. Many theories have been studied and used to explore health behaviours in relation to diabetes and other chronic diseases over the last three or four decades (Nieuwenhuijsen et al. 2006). During this time period, three key theories have emerged: The Health Belief Model, Social Cognitive Theory, and The Transtheoretical Model.

The theories noted above have been the prevailing methodologies in behavioural change approaches over recent years and each was studied and considered in guiding the qualitative aspect of this study. The Health Belief Model is most commonly used in health promotion and treatment compliance. Developed in the 1950s by Hochbaum Rosenstock, it focuses on the ways in which attitudes and beliefs predict behaviours. However, this theory is based on the assumption that individuals are affected by health predictors and manifestations and does not take into account sociological factors (Antonovsky and Kats 1970).

Social Cognitive Theory can be seen as an expansion of the Social Learning theory that was developed in the 1970s by Albert Bandura and holds the view that individuals are affected by social interaction, observation and experience. This theory is limited by the assumption that individuals have insight, understanding and interest in the health behaviours of others. The Transtheoretical model of behaviour change (TMBC) also emerged in the 1970s when Prochaska identified common stages in the health change process. This theory is often referred to as 'The Stages of Change Theory' and focuses on an individual's readiness to make health-related change

(Nieuwenhuijsen et al. 2006). Criticism of this theory has been in relation to viewing change as a linear process and not taking account of the complexities involved in many health behaviours (Brug et al. 2005).

Nugent et al. (2015) sought to explore the meaning of 'Modified Social Learning Theory' (MSLT) when they used it to identify individuals at risk of difficulties with self-management of insulin-treated type 2 diabetes, a theory which had previously been applied to this field only rarely. MSLT views health behaviour as a complex function influenced by health value and perceptions of control over health. The study used MSLT to explore the beliefs and values of 13 participants through in-depth interviews. Their results identified that using a theory can facilitate the individual assessment of behaviours in patients who self-manage a health condition. The theory allowed researchers to see the interactions between values, locus of control, self-efficacy and how these influence an individual's self-management behaviour, an important aspect of which was noted to be SMBG. However, this theory was individually focused and did not take into account other relevant factors. For example, it has been noted that MSLT does not address comorbidities, which are frequently present in patients with diabetes (Nugent et al. 2015).

The advent of these theories prompted studies to test and subsequently modify them, as well as to draw on lessons learned, to develop other models and theories, such as the Self-determination Theory, which focuses on patient autonomy in managing their health (Williams et al. 2009).

When considering wider behavioural theories, The Theory of Planned Behaviour is often applied, which explains influences on behaviour and has been previously tested on self-management behaviour. This model has aided insight into behaviours around self-management, particularly identifying barriers to its initiation and maintenance, but has limitations in addressing all moderator variables associated with self-management (Strating et al. 2006). However, based on existing evidence , as detailed in the first part of this study, to understand self-monitoring and its application to self-management in the context of the individual and the 'real world' there is an identified need to explore behaviour within a social context, given the evident differences

associated with social variables, such as socio-economic status. This marries well with the sociological approach that provides a critical perspective on human behaviour and its connection to society as a whole and it is this wider contextual consideration which is often limited and restricted in the commonly used theories mentioned above. Criticisms of these theories have been that the individual's functioning within the contextual environment is a crucial consideration when addressing how chronic conditions are self-managed but is something not adequately addressed by these theories (Nieuwenhuijsen et al. 2006).

One such theoretical model which does take a sociological approach and takes into account the complexities present with individual, their environment and in particular health systems is Normalisation process theory (NPT). This theory is noted to be of value for planning and evaluating the implementation of policies and practices. However as this theory is more focused on the process of implementing health related systems and interventions rather then considering what is currently happening in the patients world (Murray et al 2010; May & Finch 2009), it was not considered an appropriate approach for this study. However, structuration theory was identified as being a potentially relevant theory (Giddens 1984); from this point onwards, this theory was influential as discussed in detail in section 5.3.2.

2.4 Overall Aim of Thesis and Objectives

This review of the literature relating to SMBG indicates that there is a genuine lack of empirical evidence in relation to patients' actual experiences of their self-management of diabetes. While some studies have considered patient experiences, most of the literature has considered this issue from a clinical perspective and little consideration has been made about the challenges faced by individual patients in practising SMBG and how they overcome these. Moreover, little is known about why poor health outcomes persist in relation to the self-management of diabetes, despite efforts to improve education and introduce technology to assist. Therefore, the overall aim of this thesis was to identify what is actually happening in the real word in relation to self-monitoring

of blood glucose, thereby determining why health outcomes in relation to diabetes remain poor.

The first aim of the thesis was to discover the extent of the problem and identify the population groups most affected. This aim therefore necessitated a quantitative approach in order to generate statistical data covering a large sample of individuals with diabetes.

The second aim was to uncover, in greater depth, how individuals are actually behaving in relation to self-monitoring and its associated actions, why they are behaving in this way, the results of their behaviours, and those factors that contribute to how they behave in the context of their own lives and society. Therefore, this aim necessitates a qualitative study design. It was felt that the combination of providing a quantitative presentation of the extent of the problem alongside a deeper exploration of what is happening with the individual and why would allow for a more comprehensive investigation of these issues.

CHAPTER 3: PART ONE: QUANTITATIVE SCOPING STUDY ASSESSING PATTERNS OF TESTING IN TAYSIDE, SCOTLAND

3.1 Introduction

The literature review identified a need to determine the number of patients with diabetes who are testing, the frequency of their testing, and how these compared across population groups. A scoping study was therefore undertaken to answer these questions and to guide the direction of any further qualitative work.

In order to generate the information necessary to answer these questions, it was identified that an opportunity exists to obtain diabetes-related data held within a Health Informatics Centre (HIC) at the University of Dundee for the Tayside Region of Scotland. This region is noted for its similarity to many areas throughout Scotland and therefore the retrieval and analytic study of the data held within this organisation can provide information which can also be applied to other areas and can therefore be generalised throughout Scotland.

This chapter details the process of collecting and analysing these secondary data.

3.2 Rationale for the study

The uptake of reagent strips for SMBG among insulin-using diabetic individuals has previously been identified as low. A cross-sectional study in this area measured the number of reagent strips administered to patients in community pharmacies and reported that only 20% of patients with type 1 diabetes and 17% of those with type 2 diabetes obtained enough strips to test blood glucose daily (Evans et al. 1999). As this study was undertaken in the '90s, more current data are required to provide a more up-to-date picture of patterns and levels of testing.

The Tayside Region was selected in view of the provision of regional diabetes data which are collected and held within the Scottish Care Information – Diabetes Collaboration (SCI-DC) database at the Health Informatics Centre

(HIC). SCI-DC is a validated population-based diabetes clinical information system with detailed data on all patients diagnosed with diabetes in Scotland. The original SCI-DC database for Tayside (formerly known as DARTS) had 95% sensitivity for identifying people with diabetes (Morris et al. 1997). The database also records demographic data such as age and deprivation measured by the Scottish Index of Multiple Deprivation (SIMD), and clinical information, for example, hospital admission and diagnosis of other medical conditions. An additional database, MEMO, records all prescriptions dispensed in Tayside and can provide information regarding diabetic medication and testing strips dispensed to patients with diabetes in the area. This information includes the medication name, an internal code and the number of unit strip contents.

3.3 Study Aims

The aim of this study is to explore levels and patterns of self-monitoring and compare this across population groups to determine if individuals are self-monitoring as recommended.

3.3 Design

This descriptive observational study investigated the patterns and frequency of SMBG in a population of insulin-using individuals with diabetes, derived from records of reagent strips dispensed within a health board area.

The descriptive analysis consisted of two parts:

Part 1 compared annual usage of strips over a 12-year period (during the data processing it was identified that data were incomplete prior to 2004).

Part 2 employed a cross-sectional approach to identify and compare testing levels within patient groups, investigating the patterns and frequency of self-monitoring of blood glucose.

3.4 Data Sources: Study Populations

The required data were drawn from the SCI-DC dataset and collated and record-linked by the HIC. Dispensed prescribing data were also extracted from

the MEMO prescribing database. The data were then anonymised and provided to the researcher via the Safe Haven. The Safe Haven is an electronic portal that provides a secure environment within which researchers can work with confidential data. Once HIC has approved access to this environment, the researcher is able to log on remotely to a secure server located within HIC from which data cannot be copied or removed.

Data files were supplied separately for each patient group. Each dataset was linked by an anonymised Community Health Index Number (CHI). Data files included:

- Demographic characteristics: sex, anonymised date of birth, date of death, dates in and out of health region, health board code, deprivation index level, type 1 or type 2 diabetic, date of diagnosis, anonymised practice code and a rurality code;
- Prescribing for the British National Formulary (BNF) Chapter 6 – Endocrine System; and
- All General Register Office (GRO) death data: date of death, main cause of death, other cause of death and place of death.

Part 1: The population under study included all individuals (aged 13 and over), resident in Tayside with a record on the SCI-DC Diabetes clinical information system who were: diagnosed with type 1 (patient group 1) or type 2 diabetes who are treated with insulin (patient group 2), during or prior to the 12-year period of the beginning of 2000 to the end of 2011; alive throughout the study period; and were dispensed at least one prescription of insulin during this 12-year period.

Part 2: The population under study was a cross-section of all individuals resident in Tayside with a record on the SCI-DC Diabetes clinical information system who were diagnosed with type 1 or type 2 diabetes who were treated with insulin, prior to or during the three-year period of 1 January 2009 to 31 December 2011 and were alive and remained within the health board area throughout the 3-year period.

3.5 Ethical approvals

HIC already has NHS Ethical approval for studies being carried out by using anonymised data, provided that the Standard Operating Procedures (SOPs) for the anonymisation and release of the data are followed. The SOPs of HIC were closely followed during this study to ensure confidentiality and anonymity.

Ethical approval was sought and obtained prior to the collection of data from the School of Health Sciences Research Ethics Committee of the University of Stirling.

3.6 Data collection

The two study populations were defined and identified using the above datasets. From this we obtained prevalence estimates of patients who were diagnosed with type 1 diabetes and type 2 diabetes treated with insulin at any time after 1 January 2004 and prior to 1 January 2012. It was noted and confirmed by HIC that prescribing data were incomplete prior to 2004, therefore results have been reported for strips dispensed from 2004 onwards. Prevalence was calculated on a year-by-year basis, excluding deaths. We then investigated whether monitoring patterns were associated with age, sex, length of time since diagnosis and postcode measure of social and material deprivation (SIMD). This was undertaken for a three-year cross-section of the sample from January 2009 up to January 2012.

3.7 Methods

Analysis was undertaken to investigate the relationships between variables and identification of the median number of strips dispensed. Self-monitoring strip prescription codes were identified from the most recent BNF and the correct codes linked to the MEMO data base codes and the patients through the unique patient identifying number. The number of strips per unit was identified for individual prescription codes to allow calculation of the number of strips dispensed to individual patients.

For every patient, the total number of SMBG reagent strips dispensed during the relevant period was determined. This was done by identifying all relevant

dispensed prescriptions and calculating the number of strips from the following information: name of reagent strips, number of packets dispensed, and number of strips in each pack. The total number of strips dispensed to each population group was determined by adding up the strips dispensed to all patients within the group. This was done by year and for the three-year cross-sectional period.

Residential areas were categorised by Health Board Quintile (SIMD) – HBSIMD5. This is a ranking based on the patient's full postcode. Category 1= most deprived; category 5= most affluent (Scottish Government 2012).

3.8 Results

Part 1: According to the General Register Office for Scotland, from 2004 to 2011 there were between 332,861 to 350,931 Tayside residents aged 13 years and over. In 2011, there were records of 1,800 patients with type 1 diabetes and 1,994 with insulin-treated type 2 diabetes.

Table 1 presents the number of strips dispensed to patients who received strips year by year over the eight-year time period. The proportion of patients with type 1 diabetes receiving strips ranged between 64–85%. The proportion of patients receiving strips in the type 2 diabetes group ranged from 87–91%. The number of strips dispensed has generally increased over this period for both patient groups, although the type 1 group shows a dip in 2007 and 2008, which may be due to incomplete data. Testing has almost doubled for this patient group, from 833,500 strips dispensed to 1,698 patients in 2004, to 1,574,950 strips distpensed to 1,969 patients in 2011. Also, within patients with type 1 diabetes, those who are testing are now doing it more frequently but there is not the same increase noted within the type 2 group, with strips dispensed to type 2 patients increasing from 950,400 dispensed to 2,073 patients in 2004 to 1,416,200 among 2,718 patients in 2011 (Table 1).

The results also identify a number of individuals in both patient groups who had not had any strips dispensed, suggesting that these individuals are not monitoring. The proportion of patients with type 1 diabetes who received strips increased from 72% in 2004 to 80% to 2011, suggesting that there are still around one quarter of patients who are not testing at all. The approximate

doubling in the number of strips dispensed over time can be attributed almost equally to increased numbers of patients testing, and to increased frequency among those testing (as shown by an increase in the median number of strips dispensed) (Table 1). In contrast, in type 2 diabetes, the proportion who test has remained relatively stable over the study period; 88% in 2004 and 91% in 2011. The steady increases in the overall number of strips dispensed is therefore accounted for by some increases in testing frequency among those who already test, rather than being an indication of wider engagement with SMBG. The frequency of testing in this group demonstrated that half of the patients did not receive enough strips to test more than twice per day (Table 1).

Part 2: This three-year (2009–2011) analysis shows patterns of reagent strip uptake by sex, age, duration of diagnosis and deprivation category (Table 2).

There were 1,800 people with type 1 diabetes who were alive throughout the study period and remained within Tayside region within this time (Table 2).

A slightly higher percentage of women than men with diabetes received strips and there was an increased frequency of testing within older age groups in those who monitored for both type 1 and type 2 patients, although this was less pronounced within the type 2 group. Within the type 1 diabetes patients the frequency of testing was highest in the first two years of diagnosis, and for those diagnosed for more than 25 years. Of those who were more recently diagnosed, the numbers who were testing was highest within the older age groups but these patients tested less frequently. In contrast, the lowest numbers of type 2 diabetes patients tested in the first two years of diagnosis and then tested less frequently in comparison to those who had been diagnosed for more than two years. This was most pronounced in those aged 25–40 and the over-70 age group. It was noted that this may be due to these patients often transitioning from non-insulin-based treatments which would not require regular self-monitoring of blood glucose. Testing was at its lowest level in those having been diagnosed for 6–14 years and was particularly low in the 25–40 age group for this duration category. There were also observably more strips dispensed to individuals within less deprived areas (Table 2).

Again, older age groups tested more, and higher levels of testing were related to length of diagnosis. Also, as with patient group 1, this group showed lower levels of frequency of monitoring in more deprived areas (Table 2).

Table 1: Numbers of SMBG reagent strips dispensed by year and the number of patients with any strips dispensed

Year	Type 1 diabetes					Type 2 diabetes				
	No. of patients	No. of strips dispensed	No. (%) of patients with strips dispensed	Median no. of strips dispensed[1]	Median no. of strips per day	No. of patients	No. of strips dispensed	No. (%) of patients with strips dispensed	Median no. of strips dispensed[1]	Median no. of strips per day
2004	1698	833500	1225 72%	500	1.4	2073	950400	1830 88%	400	1.1
2005	1712	882250	1464 85%	450	1.2	2128	1096300	1934 91%	450	1.2
2006	1802	1100200	1376 76%	600	1.6	2273	1201350	2065 91%	450	1.2
2007	1845	536000	1207 65%	300	0.8	2228	1018100	1952 88%	400	1.1
2008	1882	648450	1179 64%	350	1.0	2246	1006555	1959 87%	400	1.1
2009	1951	810900	1337 68%	200	0.5	2466	1236950	2176 88%	450	1.2
2010	1946	1432100	1554 80%	700	1.9	2597	1352100	2337 90%	450	1.2
2011	1969	1574950	1573 80%	800	2.2	2718	1416200	2473 91%	500	1.4

[1]Among patients with any strips dispensed

Table 2: Numbers of SMBG reagent strips dispensed and numbers of patients receiving strips, stratified by gender, age and deprivation, for a 3-year period

Attribute	Type 1 diabetes					Type 2 diabetes				
	n	No. of patients with strips dispensed	% of patients with strips dispensed	Median no. of strips dispensed1	Median no. of strips per day	n	No. of patients with strips dispensed	% of patients with strips dispensed	Median no. of strips dispensed[1]	Median no. of strips per day
Gender										
Female	818	738	90%	1950	1.8	941	872	93%	1150	1.0
Male	982	845	86%	1500	1.4	1053	950	90%	1200	1.1
Age										
1 13-24	408	362	89%	1575	1.4	4	4	100%	350	0.3
2 25-40	539	451	84%	1250	1.1	70	56	80%	500	0.5
3 41-55	545	483	89%	1800	1.6	377	338	90%	800	0.7
4 56-69	233	218	94%	2350	2.1	848	789	93%	1150	1.0
5 70+	75	69	92%	2600	2.4	694	534	77%	1550	1.4
Duration of years with condition										
1 0-2	183	162	88%	2100	1.9	102	77	75%	900	0.8
2 3-5	190	168	88%	1652	1.5	192	174	91%	1250	1.1
3 6-14	504	433	86%	1300	1.2	932	859	92%	1000	0.9
4 15-24	427	367	86%	1600	1.5	615	568	92%	1400	1.3
5 25+	496	453	91%	2050	1.9	153	144	94%	1300	1.2
Age groups within each duration category										
1. (0-2) 13–24	98	90	88%	2150	2.0	-	-	-	-	

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25–40	45	37	82%	2100	1.9	14	9	64%	300	0.3
41–55	24	20	83%	2575	2.3	33	23	70%	800	0.7
56–70	12	11	92%	1270	1.2	40	37	92%	1400	1.3
70+	4	4	100%	1750	1.6	14	7	50%	1050	1.0
2. (3–5)										
13–24	78	68	87%	1625	1.5	2	2	100%	300	0.3
25–40	60	52	87%	1125	1.0	26	22	85%	675	0.6
41–55	37	33	89%	2200	2.0	50	48	96%	900	0.8
56–69	12	12	100%	2350	2.1	78	71	91%	1850	1.7
70+	3	3	100%	3250	3.0	36	31	86%	1500	1.4
3. (6-14)										
13–24	195	174	90%	1350	1.2	2	2	100%	450	0.4
25–40	171	138	81%	875	0.8	2	22	81%	500	0.5
41–55	95	82	86%	1375	1.3	7	195	91%	800	0.7
56–70	28	26	93%	2800	2.6	2	382	94%	1050	1.0
70+	15	13	87%	3850	3.5	1	258	92%	1500	1.4
4. (15–24)										
13–24	36	30	83%	675	0.6	-	-	-	-	-
25–40	181	147	81%	1500	1.4	3	3	100%	300	0.2
41–55	161	144	98%	1725	1.6	73	66	90%	675	0.6
56–69	34	33	97%	2150	2.0	262	242	92%	1300	1.2
70+	15	13	87%	2550	2.3	277	257	93%	1600	1.5
5. (25+)										
13–24	1	-	-	-	-	-	-	-	-	-
25–40	82	77	94%	1500	1.4	-	-	-	-	-
41–55	228	204	89%	1975	1.8	6	6	100%	900	0.8
56–69	147	136	93%	2450	2.2	60	57	95%	1050	1.0
70+	38	36	95%	2650	2.4	87	81	93%	1500	1.4

Deprivation Quintile										
1(most deprived)	324	287	89%	1350	1.2	448	412	92%	1000	0.9
2	364	312	86%	1400	1.3	426	392	92%	1025	0.9
3	342	308	90%	1825	1.7	394	357	91%	1350	1.2
4	389	334	86%	2000	1.8	373	341	91%	1150	1.0
5 (least deprived)	312	284	91%	2100	1.9	307	292	92%	1350	1.2
[1]Among patients with any strips dispensed										

3.9 Discussion

Despite a growing body of evidence identifying the importance of SMBG in maintaining glycaemic control and in turn decreasing the risk of diabetic-related complications, many patients with type 1 and type 2 diabetes are not self-monitoring as per the guidance and, more importantly, some are not testing at all (up to 36% in type 1 and up to 13% in type 2). Interestingly, this level of non-testing has changed slightly from the previous 1993–1995 study; increasing for type 1 patients (previously reported at 16%) and decreasing for those with type 2 diabetes (previously reported at 21%), therefore there is no improvement in the level of type 1 patients who are not testing. However, there is some improvement for those who are type 2 and not testing. We know that the recommendations for testing in type 1 diabetes range from once daily to 4 times daily, with frequency and timing adapted to individual patient requirements. Guidance for type 2 diabetes suggests that routine testing should only be undertaken by those treated with insulin and that HCPs evaluate 'temporal patterns' so that medication can be appropriately adjusted (Hansen et al. 2009; NICE 2015; Nomura 2002; SIGN 2010). Clearly, from the results reported here, the number of strips dispensed to individuals is not close to the amount and frequency of testing which are recommended in clinical guidelines.

Reagent strip uptake also depends on patient characteristics such as gender, age and social deprivation category. This finding is consistent with those reported in the previous 1993–1995 study. It should be noted that, as discussed within the literature review section (Chapter 2, section 2.2.2), although the SIMD tool is well used and accepted, there are limitations in its efficiency to calculate levels of deprivation. As the tool is broad, using postcodes to determine deprivation levels, it does not account for variations within areas. The strengths of this data analysis are in its ability to identify the level of testing strips being dispensed to a wide health board population group. By calculating the number of strips dispensed, rather than other studies which calculate strips prescribed, a more accurate picture is presented; as we cannot be certain that all prescriptions prescribed are actually dispensed. However, the limitations of calculating reagent strips dispensed as a proxy for monitoring frequency should be noted, that is, the uncertainty that patients actually use all

strips dispensed to them, and the possibility that they may have received strips from other sources.

It is noted from the literature review and this quantitative study that individuals with diabetes are not self-monitoring their blood glucose in line with what is recommended by clinical guidance. These quantitative data provide a clear picture that patients with diabetes who are recommended to self-monitor their blood glucose several times a day are not doing so nearly as frequently as they should be and, in fact, some are not undertaking any self-monitoring on a daily basis. Based on this information there is a need to explore why patients are not taking on board the importance of this key part of their self-management and, more importantly, how the omission of undertaking this process as they should be is influencing their overall diabetes self-management.

The quantitative analysis was descriptive and suggested that many patients were not self-monitoring as frequently as they should be, and that some were not self-monitoring at all. In order to generate a deeper understanding of the reasons for this, it was determined that a subsequent exploratory study of individual behaviours was required, underpinned by a theoretical position that considers all factors relating to the patient as well as the wider societal influences. Based on the overall focus on the qualitative element to this study there was no further statistical analysis required for the quantitative scoping of the study.

This quantitative study has been recently published in an academic journal in the form of a short report (Appendix 1).

CHAPTER 4: PART TWO: AIMS & METHODOLOGY OF THE QUALITATIVE CASE STUDY

4.1 Study aims and research questions

The scoping study undertaken in the quantitative part of this research has identified that patients for whom guidance directs self-monitoring of blood glucose are not doing this as regularly as they should be and some are not self-monitoring at all. Other quantitative studies that have identified a link between SMBG and glycemic control have reported a need to understand the mechanisms underpinning action (Breland et al. 2013). Therefore, it is imperative that we explore the practical implementation of SMBG to understand the factors contributing to the successful application of self-monitoring results to self-management and why those factors are important. Much of the literature in this field is descriptive in nature and there appears to be a need to move beyond description to seek further understanding of the associated mechanisms and the interplay of variables which can influence self-management practices in SMBG.

The aim of the qualitative element of this thesis was to explore in depth the process of SMBG and, specifically, the factors that have an impact on the effective use of SMBG results in the context of everyday lives, in order to obtain insight and understanding into why individuals behave in certain ways. Through identification of influencing factors and their importance there may be the potential to influence change. The holistic approach to this in depth exploration required a multifaceted approach whereby the perspectives of people with diabetes, their family/other supporter and HCPs were deemed important in the examination process. The research intended to identify influences on current practices and behaviours surrounding self-monitoring, thus providing insight and a deeper understanding of the application of SMBG. This presented the potential to inform future research as well as educational and management interventions around SMBG.

4.1.1 Research questions

Two key question areas (each with sub-questions) emerged around particular aspects of SMBG behaviour:

Question 1: What are patients doing in relation to SMBG in the context of their lives and the structures around them?

- How do patients currently use their results/data from SMBG to manage their condition and what are the outcomes in terms of 'problem solving'?
- Do patients keep records and do they share them with HCPs?
- Do patients utilise 'pattern recognition' and 'new technology', is this assisting with their management, how well is this understood and is this being integrated into health services?
- What are the most effective ways to provide education and what is the evidence base?
- How do health services influence patient practices?
- How do support people influence patient practices?

Question 2: What are the HCP and support people's perspectives in relation to self-monitoring: what are their understanding and views around SMBG and associated management?

The following section justifies the methodological approach taken for this study, providing a critical analysis of the use of case study in this type of research. This is followed by a description of the study methods.

CHAPTER 5: METHODOLOGY

As noted in the previous chapter, there is demonstrated need to study HOW these individuals are testing in the real world setting, ensuring the identification of the contextual aspects of people's lives (Yin 2014). The research questions were designed to explore why people are undertaking SMBG in the way that they are and how their results are used to assist wider diabetes self-management. These questions emerged from the knowledge and information available at the outset and during the design phase of this study. However, there was an awareness that following the process of exploring issues in-depth, with little idea of what would emerge, the theoretical perspective at the end might differ from that at the beginning. In order to investigate these questions in depth and to enable such views, experiences and opinions to be explored from the world of those who are living the experience, a case study design was employed.

5.1 Case Study

This section will explore the case study approach and the rationale for its application within the proposed research.

Self-monitoring of blood glucose happens in the real world and the real world is complex; "no behavior occurs in a vacuum, it occurs in the context of others" (Thomas 2011, p. 53).

The case study approach can move beyond descriptive research to provide rich information with the aim of understanding the interplay of variables which can influence outcomes, thereby offering insight for future research and practice. Yin (2003) refers to case study as an empirical inquiry, investigating a contemporary phenomenon in a real-life context (Yin 2003). This study seeks to explore processes and behaviours that happen in the real world. This requires the generation of rich information which cannot be obtained via a quantitative study design. The type of in-depth exploration needed requires a holistic approach, looking at 'the whole', which can be generated with a case

study utilising multiple sources of data, rather than the linear approach advocated by some other methodologies.

Adopting an interpretivist approach to analysis will allow for the conceptualisation and contextualisation of SMBG, taking into account the complexities of the social world to provide a holistic picture. In addition, this approach will facilitate the emergence of links between variables related to the self-monitoring process, thereby identifying the relevant explanatory factors (Thomas 2011).

The value of case studies in health research is clear in terms of their flexibility to collect, probe and present detailed information on a group of interest with the purpose of asking 'how' and 'why' questions, and in the ability to gain multiple perspectives to contextualise the topic of interest (Thomas 2011). However, it should be noted that a number of criticisms are directed toward case study research. It is common, for example, to read of condemnation of the scientific rigour and generalisability of the case study (Johnson 1994).

Consequently, despite the fact that case study research has been undertaken for many years in the health disciplines, particularly because of its ability to incorporate the contexts of the real-life, some in health care remain reluctant to endorse this approach (Johnson 1994). In defense, Luck et al. (2006) point out that the flexible case study method, which has the capacity to study the process as well as the end product of research, is in fact under-utilised in the healthcare setting and it is because of the recognised value of this study design that case study is now gaining popularity in health service research. Moreover, it is somewhat ironic that a vast amount of empirical findings are derived from case studies, but this method is sometimes not viewed favourably and is therefore frequently overlooked (Johnson 1994; Luck et al. 2006).

In other words, it is important that the methodological approach takes into consideration these complex factors of the real world and how their interrelation can affect behaviours. This study sought to explore the processes and behaviours around SMBG to generate rich data which provide insight into the individuals, their associated factors, and the interactions between the two. In-

depth inquiry, a holistic point of view and relevance are considered more valuable than generalisation, with the ultimate purpose of informing users and providers of services with a view to aiding self-management through a deeper understanding, therefore contextualising with the purpose of informing services, for both users and providers (Thomas 2011).

To identify the appropriateness of case study design over other types of qualitative methods, an assessment was used to distinguish the relevant situations for different research methods. Three conditions were assessed; firstly, the research question posed is 'how and why'. This fits with case study, experimental and history research design. The second condition is the extent of control that the investigator has over actual behavioural events. For this particular research the investigator has no control which fits with all types of methods other than experimental methods. The third condition is the level of focus on contemporary rather than historical events and for this study the focus is on what is happening currently with SMBG and therefore has a contemporary focus (Yin 2014). This fits with all methods other than history research. In summation, case study research was the method which fits with all the conditions of this study's aims and objectives.

When studying process and meaning, the methodological focus is interpretation rather than statistical generalisability. Generalisability cannot be taken as read in qualitative studies but this is not to say that we cannot generalise to some extent in qualitative research. In order to ensure quality and credibility, it is important to apply structure to the research. This can be done by employing a theoretical framework. In addition, when addressing such criticism it is important to understand that a case study is not intended to study an entire organisation or population. Rather, the emphasis is on a particular issue enabling the examination of complex real-life processes (Noor 2008). This study proposes to utilise Stones' Structuration theoretical framework detailed above (sections 4.2 and 4.3), as a theoretically-driven case study ensures meaningful research, where understanding is generated through explanation of specific social processes within immediate as well as wider social contexts (Mills et al. 2010).

To gain insight into concepts which may explain individual behaviours, multiple sources of evidence should be used, rather than relying on a single source (Yin 2014). With this in mind this case study was designed to use multiple data sources.

When designing a case study, the four conditions of test are:

1. Construct validity,
2. Internal validity,
3. External validity, and
4. Reliability. (Yin 2003)

When addressing the criticism of lack of generalisability, it has been noted that generalisability can be gained by using multiple case studies (Noor 2008). Hence, this study has utilised a multiple case study approach, as the study of a number of cases jointly allows measurement and explanation of links between dependent and independent variables and in turn compares relevant factors. The utilisation of several separate cases provides richer information, understanding and meaning (Thomas 2011).

5.2 Study Methods

This section details the population of study, the sample and methods, the methods of analysis, the role of the researcher, and ethical considerations.

5.2.1 Population

The study population of interest was defined as patients with diabetes attending an Outpatient Clinic within a health region in Scotland. Patients were included if they were adults, had been diagnosed with diabetes mellitus 1 or 2, and treated with insulin.

Patients were excluded if they were pregnant, as pregnancy is often a time when health behaviours change, or were not capable of understanding or providing informed consent (see Table 3).

A case was defined as a participant, along with a support person, and/or a nominated HCP, plus a patient diary. Participants identified their key support

person: this could be a friend, relative, or work colleague; or an individual who supports them in some way with their diabetes. This could simply be someone who they discuss their self-management with. The participants also identified their key HCP: this could be their diabetes consultant, diabetes specialist nurse, dietician, practice nurse, GP, or podiatrist; or an HCP who they feel assists with the diabetes management.

5.2.2 Recruitment and consent

Informed consent, a legal requirement of research, was obtained to ensure participant understanding and also allowed an opportunity for participants to decline to take part in the research (see consent forms, Appendix 2).

Information was provided in the form of: patient information material and support person/HCP information material (see Appendix 3), which outlined the aims of the research and what was required of the participants. This also pointed out how confidentiality and anonymity would be maintained, ensuring that patients understood that withdrawal at any time during the process would be treated with respect and that their data would subsequently be removed from the study if they did so (Data Protection Act 1998).

Recruiting the patients

Sixteen patients were selected from Diabetic outpatient services. Diabetes Clinic Consultants identified eligible patients and then provided them with a patient information leaflet and consent form. Patients were initially selected on the basis of convenience and selection continued until 10 participants consented who demonstrated reasonable variation.

Recruitment of HCP and Support Person

Each consenting patient identified their key HCP and support person, as outlined in the inclusion and exclusion criteria. The patient was responsible for providing the identified HCP and Support Person with study information and a consent to contact form along with a stamped addressed envelope. On receipt

of the consent to contact form, the HCP or support person was then contacted to arrange the telephone interview.

Table 3: Inclusion and exclusion criteria

People involved	Inclusion criteria	Exclusion criteria
Patients	1. Diagnosed with Diabetes Mellitus, Type 1 or Type 2 treated with insulin 2. Patient who are ≥ 18 years of age 3. Patients who are fluent in English 4. Competent to consent to participate in the study	1. Diagnosed with Diabetes Mellitus which is treated by diet and/or oral medication 2. Patients < 18 years of age 3. Patients who are pregnant 4. Patients not fluent in English 5. Patients who do not wish to participate, or who are unable to consent
HCP	1. Qualified HCP 2. Identified by the consenting patient as part of the multidisciplinary team responsible for the management of their diabetic care 3. HCP who is fluent English	1. Non-qualified health workers 2. No responsibility for diabetic management of the consenting patient 3. Bank or agency health workers 4. HCP not fluent English
Support Person	1. Individual identified by consenting patient as involved in the management of their diabetic care 2. Person who is fluent in English 3. Person who is ≥ 18 years of age.	1. Not fluent in English 2. Person who is < 18 years of age

5.2.3 Data collection

Sample

As diabetes can affect and present in all ages and all population groups, although with a stronger prevalence among those living in more deprived areas, the aim was to obtain a wide variety of representation of individuals with diabetes. We aimed to include individuals with both type 1 and insulin treated type 2 diabetes, males and females, older, middle aged and younger adults and those from different socio-economic classes and with different educational levels. In addition, we aimed to obtain varied representation of HCPs who support patients with their self management. A convenience sampling strategy was used to recruit the individuals with diabetes whereby patients attending general diabetes outpatient clinics for patients with type 1 and 2 diabetes, including a young adults' outpatient clinic, were invited to speak with the researcher. Participants were advised that supporting HCPs could include: their hospital consultant, GP, practice nurse, dietician, podiatrist or diabetes specialist nurse; but it was their decision as to whom to invite.

The final sample consisted of 21 individuals: ten patient participants, seven support people, four HCPs and six patient diaries (Table 4).

Table 4: Data

Participants	Support People	HCP	Patient Diary
10	7	4	6

An iterative process was used in sampling, whereby as data were collected, a preliminary assessment was made of the data which then shaped subsequent sampling decisions. The final sample which aimed to capture a range of the population included six type 1 patients and four type 2 patients; four females and six males; three patients from deprived areas and seven from less deprived areas; and five older people (over 60 years), four middle-aged (40 to 60 years)

and one young adult (18-25 years). This shows that there was variability in the sample, with different groups represented.

The four HCPs in the final sample included two medical consultants, a podiatrist and a specialst dietician. The seven support people included a husband, two wives, a mum and three partners.

Following the interview with participant 9, some saturation was noted. Saturation occurs when, after a period of time of asking participants the same questions, the researcher then notes that the data being gathered from interviews are no longer generating new insights or ideas (Creswell 2014). One further participant was recruited following saturation at which point it was noted that the sample consisted of a varied mix of the population with insulin-treated diabetes.

Additional authority and rigour was afforded through additional interviews and supporting data. Interviews and patient diaries were piloted and, as they complemented and enriched the findings, these were also included within the data. This included two pilot telephone interviews with support people of patients with diabetes, three pilot patients' diaries and one HCP, a diabetes consultant who was asked to comment and provide interpretation of all patient diaries.

It was ideally hoped to obtain a mix of views around each case, but it was not possible to obtain a full complement for all cases as two participants were unable to identify a support person and not all support people and HCPs consented to be contacted. In addition to this, not all participants returned the patient diary. Figure 2 demonstrates the support data provided for each case that were collected for this study.

Although it was hoped that the HCP perspective would be obtained through exploring the views of a wide range of HCPs, there were noted difficulties in recruiting HCPs from general practice. This was noted early on in the process when consent to contact forms were not received from several of the participants who identified HCPs in general practice. In an attempt to overcome this lack of response, the researcher contacted the participants to determine

whether the consent to contact information had been passed on to these HCPs. Participants were able to confirm this and were thereafter asked to remind their HCPs to return the consent on their next visit. This was problematic when there was some time until their next visit and resulted in limited representation from general practice.

Data were collected firstly to explore participants' understanding of their condition, and the associated management as well as experiences, and secondly, to explore patient practices in relation to SMBG and actions following testing including problem solving and analysing results. Further, they were used to examine what influences these practices, particpants' opinions in relation to practices, and how their knowledge and skills had been gained and had developed over time.

Confidentiality and anonymity

A recruitment log was kept for all participants, with each participant being assigned a unique identification code. Confidentiality and anonymity was maintained at all times, all transcripts were anonymised, and participants were assured that all information provided would be kept confidential. All study information is held in locked files within the University of Stirling.

Figure 2: Cases for Multi-Case Study

In-depth, semi-structured interviews

In-depth, semi-structured interviews with each of the participants was the chosen method of data collection. This method was selected as it allowed adequate coverage of the research questions and the depth of insight required. The interview schedule contained major questions established in the form of a broad statement, followed by a number of loosely structured sub-questions to allow additional probing and to guide the conversation (Noor 2008; Yin 2014). The major questions were structured around the research questions, the themes which emerged from the literature review, and areas of the theoretical framework. Attention was paid to ensure that questions were phrased carefully to facilitate the exploration of experiences without making patients feel that they were being judged (see patient interview schedule, Appendix 4).

Motivation was addressed within the interview schedule. Motivation is influenced by how important the health-related issue is to the individual as well as how confident they feel about managing health behaviours. When assessing motivation in health care, a one-to-ten scale is often used to make this assessment, providing a comparison to be made between the individual's perceived importance and confidence in relation to health behaviours (Rollnick et al. 2008). This assessment scale was therefore integrated into the interview schedule to identify each participant's level of motivation.

The interview questions were then piloted with two of the researcher's contacts to identify ambiguities and ensure clarity of questioning. This method of questioning allowed the participant to articulate explanations and meanings, as well as allowing the researcher to seek clarification (where necessary).

Face-to-face semi-structured interviews were undertaken with each of the 10 patients, during which each patient identified their key HCP and key support person. Two participants who lived alone were unable to identify a support person, even after probing to explore all possibilities. In-depth telephone interviews were then undertaken with the support people and HCPs identified by the participants.

Patient Diary

Each participant was asked to complete a diary over a two-week period. A two-week period was considered reasonable in terms of not being too intrusive and labour-intensive. Participants were asked to select a normal/regular two-week period, when they were unlikely to be doing anything out of the ordinary (for example, any holidays or organised significant life events).

An open format was used to allow respondents to record activities, events and feelings in their own words. It was expected that patients would provide some record of SMBG results, but the focus was to encourage them to note their thoughts, interpretation and actions. The diary contained instructions regarding the completion of the diaries and the information required as well as example diary entries (see Appendix 5). In addition, explicit verbal advice about completing the diary was provided to each participant during the face-to-face interview.

Two pilot diaries were completed by personal contacts of the researcher who were insulin-treated individuals with diabetes. Feedback from the pilot participants and analysis of the diary extracts informed amendments, which included:

- Example of diary entry was changed from one body of text to two separate entry boxes: When and Why. This was to encourage more descriptive data, rather than just a list of times and SMBG results. The format for each daily entry was also changed in line with the example diary entry

Telephone interviews

Where possible, telephone interviews were undertaken with each participant's consenting HCP and support person. These in-depth interviews were also semi-structured. Again, major questions were structured around the research questions, themes emerging from the literature review and areas of the theoretical framework (see HCP interview schedule in Appendix 6, and Support Person interview schedule in Appendix 7). The additional data generated

through these interviews were used to assist with gaining insights into all the dimensions of the processes of SMBG.

The calls were made from Skype to landlines using Ecamm digital call recording. This allowed the researcher to split voices and to add markers during the calls for each question. All digitally recorded calls were then transcribed verbatim using Express Scribe computer software. Digital recordings were then stored on a USB stick which was then locked in a secure filing cabinet along with the written transcription material within the University of Stirling.

5.3 Data analysis

An interpretive approach was applied at the first stage of data analysis with a view to supporting the emergence of meanings which are constructed through the data. Interview transcripts and diaries were read repeatedly with the purpose of understanding actions and behaviours (Miles and Huberman 1984).

QSR NVivo (V10) software was then used to first store this raw data and then go on to organise, categorise and code the data. The researcher attended introductory training in the use of NVivo and also used self-help published material in addition to supervisor guidance.

A constant comparative method (CCM) was applied using a staged approach. The first round of this staged process was open coding of the data by re-reading the transcripts to develop categories and then further reducing and recoding. As the transcripts were re-read, themes and patterns were noted as they emerged, which were based around (but not confined to) the research questions. An inductive approach was used to allow these themes to develop. At this stage, a theoretical model was introduced to assist with the analysis. As the data were coded, the coding was organizing into the themes which were organised into sections and mapped on to a conceptual model based on Stones' structuration theory framework. A conceptual framework was then developed, mapping the key categories emerging from the data. All data were then systematically and continually compared to all elements of other data in the dataset. This subsequently allowed for the emergence of themes, and these

were examined for evidence that was consistent across themes. Variation in views were considered and, further on into the CCM process, the data were examined to identify and explain disconfirming evidence, thus providing a marker of quality and validity to the research (Creswell 2014). In addition to this, transcripts and emerging themes were discussed with supervisors as an additional check on the reliability and credibility of the researcher's interpretation.

Specifically, the steps after categorising were:

1. Comparison within the single interview,
2. Comparison with the case (including supporting evidence),
3. Comparison across interviews,
4. Comparison across cases and across supporting evidence, and
5. Identification of disconfirming evidence.

Although the qualitative case study approach to the research was based on Yins (2014) work, the literature identifies several approaches to case study analysis, including the constant comparative approach of Miles and Huberman (Tight 2017). The reason for considering this approach to analyzing the data was that one of the key requirements within a case study is to generate meaning from the data. The constant comparative method of analysis involves comparing the data; incidents and situations to generate meaning within the categories throughout the process. Case study requires a holistic approach where all associated factors are considered. The constant comparative approach considers the full breadth of influences on each of the categories and emerging themes and the relationships between these categories and themes (Glaser 2008).

5.3.1 Integration of a theoretical framework

Based on the review and critique of health related behavioural theories, an exploration and consideration of various sociological approaches highlighted how social phenomena are a product of social structures combined with social action rather than being one or the other. One such sociological approach is provided by structuration theory, and Rob Stones' version in particular is one

that is applicable to studying human activities action (in this case, SMBG) within a context of social structures. The appraisal of Health Behaviour Theories, discussed in section 2.4, provided an understanding of the many theoretical perspectives and highlighted the need for a sociological approach in this study, one which is all-encompassing. Rob Stones' version of structuration theory appeared most fitting as it adopts the notion that individual decision making and actions are dependent on a person's nature and capabilities which in turn are affected by wider structures. The distinctiveness of this theory is that it goes beyond just structures and agents within a system; it methodically, phenomenologically and philosophically conceptualises structures and their associated agents (Stones 2005).

The study of theoretical frameworks was an evolving process, commencing during the literature review and extending through the field work stage.

5.3.2 Structuration Theory

Structuration theory was developed by Anthony Giddens, a sociologist whose work has provided a basis for empirical sociology over the past four decades (Giddens 1984). Structuration theory originated from a two-part concept: 'structure and society' (being rules and resources in society); and 'agents and society' (being humans within society), which acknowledges the equal importance of both elements in human activities and allows for the exploration of their interrelationships and interdependencies. Giddens describes how these elements feed back into social structures, reproducing and shaping them, in a process sometimes referred to as the 'duality of structures' (Giddens 1984). Hence, the distinctiveness of this theory is that it provides the ability to study both agency and structure together; how they interplay and influence one another, rather than looking at them individually and in isolation.

Giddens suggests that sociological research is characteristically critical and therefore requires 'reflexivity' and 'dialogue 'to highlight 'social life'. Specifically, the researcher needs to constantly be aware of how trustworthy the study participants' actions and statements are (Hardcastle et al. 2005). Giddens applied the notion that discrepancies, between what participants say and what

they do in practice, should be seen as facilitators to uncovering topics, as opposed to a weakness (Giddens 1984). This appeared to be of relevance to this study topic in view of the need to really understand what is happening in practice in relation to self-monitoring of blood glucose.

Criticism relating to Giddens' structuration theory has been that it fails to demonstrate the application of the theory to practical contexts. However, Stones' version responds to this critique, as his version not only presents the philosophical roots of the theory, but also considers how it might be applied at both a conceptual and contextual level (Stones 2005).

In Stones' version, he performed extensive studies of social and sociological theories and their use in empirical case study research. Building on structuration theory, he developed 'Strong Structuration Theory' to address the complexities and contradiction of social order in the modern world. This version of the theory explores more deeply how individual and organisational knowledge and values are influenced by external structures, how they are developed and how they in turn influence actions (Stones 2005). In seeking to provide a framework to address the criticism that structuration theory has little place in the modern world, Stones' framework moved from a discrete two-pronged model to considering the duality of the theory within four dimensions, known as the Quadripartite Nature of Structuration. Here, four separate but inter-linking aspects deal with the duality of structure to demonstrate how the theory can provide a robust and critical perspective:

1. External structures: the physical, social or economic environment where actions are considered and happen; this is influenced by social status (constraining or influencing).
2. Internal structures: individual background, knowledge and experience as well as morals, beliefs and skills.
3. Active agency; this is how the individual draws on their knowledge, experience and skills which informs their actions and choices.
4. Outcomes: of the active agent, which can feed back to the external and internal structures, reproducing and/or changing.

This version takes into account that societal influences are not limited to an individual's own internal structures (an individual's background, knowledge, skills and beliefs), but that influences can also be affected by an individual's perceptions. For example, how a person behaves can be influenced by what a person assumes their consultant expects of them.

This version of the theory combines consideration of external social structures independent of an individual's knowledge and perception, as well as internal structures, based on what the individual knows. Therefore, this fits with the study of human action and choice within the context of the real world (Hinder and Greenhalgh 2012).

The purpose of using structuration theory within this study was to provide the depth with which to conceptualise SMBG in the context of wider self-management and to provide a bridge to link the individual with structural and sociological factors. This facilitated the generation of knowledge and comprehension of how individuals develop and reshape structures and therefore whether there is potential to influence change. The selection of structuration theory to underpin the study and integration of this theoretical framework was an evolving process. It was integrated into the study following collection of data at the point of mapping the results and the commencement of analysis.

The themes and headings listed below are the key themes emerging from the first stage analysis which were then mapped around the four main areas of structuration theory:

- ➢ External Structures (wider context in which action is contemplated and takes place)
    - Social, work and family situation
    - Health services
    - Clinical guidelines
    - Health Care Practitioners
    - Primary care
    - Individualised care

- Goals and targets
- Government and Policy

- Internal Structures (what individuals know)
  - Background
    - Support people
    - Past experiences
    - Diagnosis
    - Morals
  - Facilitators
  - Barriers
    - Pain
    - Self-consciousness
    - Resource
    - Access
    - Time
  - Understanding
    - Demonstrating understanding
    - Risks
    - Concern regarding high and low blood glucose levels
    - Education

- Active Agency (what they do)
  - Behaviour
    - Motivation
    - Don't test as don't want answer
  - Problem Solving
    - Pattern Recognition
    - New Technology
    - Literacy
    - Numeracy
    - Confidence
  - Actions

- o Device
- o Recording Results
- o Frequency and Timing of Testing
- Review
  - o Sharing results
- Control
- Rationale for testing
  - o SMBG for safety
  - o Physical signs
  - o Importance
  - o Routine
- Views/feeling
  - o Emotion
  - o Responsible for own health
  - o Labeled with condition
  - o Feeling controlled

> Outcomes (intended and unintended which may impact on external and internal structures and may be reproduced or changed)
- Clinical outcomes
- Quality of life
- HbA1c
- Diabetic-related complications

During this process, a model (Figure 3) emerged which again assisted the researcher to move easily between themes.

Figure 3: Coding informed by Structuration Theory

These were the temporary construct themes. Each coded theme was then re-read and analysed in detail to identify those themes which were most reinforced across all of the data.

A within-case analysis was then undertaken, as conclusions were beginning to be drawn from the data. Support person interview data and diary extracts were used for the within-case analysis and as supporting evidence. HCPs have been grouped to form an additional case and these data have been used as supporting evidence for the cross-case analysis. There were varying levels of response from HCPs, support persons and for the completion and return of the diaries, therefore each case has different degrees of case evidence.

To provide additional clarification on diary extracts, a Diabetes Consultant was asked to comment and provide her opinion on the extracts; these data have been included.

5.4 Ethics

5.4.1 Ethical Considerations

In addition to the ethical considerations of providing participant information and obtaining consent already referred to within the recruitment and methods sections there were further ethical considerations which required attention within this study. As the researchers were unable to contact identified health care professionals directly, the most appropriate route to contact these HCPs was through the participants themselves. This was effective for some HCPs but was noted to be dependent on the type of clinical environment and structure they work in.

Pressure to participate was also an important area of consideration. This was addressed by ensuring the invited participants had a period of time (48 hours) to review the patient information before agreeing to participate in the study. In addition to this, potential participants were not approached directly, they were asked to complete a consent to contact before being approached by a member of the research team.

There were also ethical considerations relating to the patient diary. It was important to ensure the diary would not be too onerous and potentially result in participants not completing the diary at all. Taking these considerations into account, a two week timespan for the diary was deemed a reasonable expectation. This was based on trialled the diary with two personal contacts. Feedback evaluation was received relating to the content of the diary as well as time required to compete the diary. From this evaluation it was deemed that two weeks was a reasonable length of time to request diary completion and not too onerous for participatants.

Anonymity of participants was deemed important and all data and analytical documentation were anonymized.

Ethical Approval

Study protocols for this research were approved by the Ethics Committee of the (then) School of Health Sciences (SREC), University of Stirling. Application for ethical approval was then made and gained from the NHS National Research Ethics Service serving this Scottish Health region. R&D approval was also obtained from the study site (Appendix 8).

5.4.1 Risk management in ethics

It was acknowledged that the participants involved in the research may be at risk of experiencing embarrassment, guilt or distress when asked to disclose personal information relating to knowledge and attitudes. It was determined that where participants experienced obvious distress the researcher would suspend the interview and recommence with the participant's full consent. If ongoing distress was noted or reported, participants would be referred to the University of Stirling Counselling Service. There were no reported or observed situations requiring this management.

Health and safety risks were also deemed minimal other than 'repetitive movement' and lone working, including driving to and from participants' homes and interviewing them there. The appropriate personnel were contacted with regard to risk assessment at the outset of the study and relative risk

assessments were undertaken. A 'lone worker' policy was put in place whereby the researcher checked in and out with a named contact when visiting participants in their own homes.

The potential benefits of the research were the identification of factors which influence self-monitoring of blood glucose which could contribute to the development of strategies and future research to assist patients to effectively self-monitor the blood glucose to self-manage their diabetes. The likely benefits of the research were perceived as greatly outweighing the risk of discomfort to patients, their supporters and clinicians.

5.5 Reflexivity and the role of the researcher

The researcher recruited the 10 participants and undertook the face-to-face interviews, explanation of the diary and identification of their key HCPs and support people, and subsequently undertook the telephone interviews with those who agreed to participate.

The researcher has a clinical nursing background working for several years in primary care as a practice nurse and community nurse, and with an interest in diabetes through the management of diabetes clinics in general practice and individualised care within the community. This background knowledge of diabetes and how it is self-managed assisted the researcher to understand some of the common issues facing patients in relation to their condition. This allowed the researcher to understand and interpret interview content. In addition to this understanding of the condition and how it is managed, the years of experience gained through clinical work in this area allowed the researcher to effectively engage and communicate with patients, therefore encouraging depth in conversation and in the exploration of this topic.

While the benefits of the researcher's background were noted, there was also the awareness of clinical assumptions being made, based on previous experience. To avoid this potential bias, the researcher approached each interview with an open perspective. Transcribing the interviews verbatim also ensured that all information was taken into consideration and the constant comparative approach allowed the researcher to revisit all data. Furthermore,

one supervisor, who has a background in social science, helped to ensure that wider perspectives on the data were gathered.

The researcher recognised that by undertaking all of the interviews she was therefore integral to the research process. By acknowledging the influence that the researcher has on the research process, she was able to take this into account throughout the study in a process known as 'reflexivity'. Reflexivity is an important element of all research, if only overtly in qualitative inquiry. As Alvesson and Skoldber (2009) point out, the relationship between researcher and research participant is mutually reinforcing; there is 'no one-way street' in the research process. McNair, Taft and Hegarty (2008) address the importance of clinicians undertaking research, arguing that the clinician is a valuable resource in the research field in terms of their knowledge and experience as well as being well placed to access participants and information. In particular, where clinicians interview patients and other clinicians, there is a shared understanding and interpretation during the research process. Thus, their involvement in research, contrary to the traditional view that clinical researchers should be removed from the research process, is acknowledged as an inevitable feature of data gathering as well as interpretation (McNair et al. 2008). With this in mind, the researcher was sensitive to the possibility that participants may feel that they were being judged on their knowledge and understanding and therefore she encouraged them to feel at ease in relation to their responses. Hence, reflexivity involves the judgement and ability of the researcher to 'see and point something out' (Alvesson and Skoldberg 2009) and to acknowledge the influence of the researcher. This is not to imply that 'anything goes', but rather, to argue that the researcher's experience and knowledge, along with the study methods and theorising, are always brought to the process of the interpretation of data.

5.6 Summary

This chapter explored the concept of the case study approach and argued the strength of theoretically-grounded case study research. The constituent methods of the research process were then described in detail and justified. The following chapter is the results chapter, where the outcomes are firstly

presented descriptively, after which it moves through the stages of the analytical process. The results are organised broadly around the researcher's pictorial version of Stones' structuration theory (Figure 3).

CHAPTER 6: RESULTS

6.1 Introduction

This exploratory multi-case study investigated the many contextual factors that might influence and affect how an individual self-monitors their blood glucose as well as their implications for diabetes self-management. The presentation of the results is structured to demonstrate the progressive analytical process. It should be noted that, within this section, the participants and HCPs use varying language when describing their results from self-monitoring, for example, 'good', 'normal', 'abnormal' and 'unstable'. However, what the participants perceive to be satisfactory or what they understand to be 'normal', is not always what the HCPs managing their condition consider to be an optimal level and vice versa.

6.2   Within-Case Analysis

Each case was analysed in turn, identifying key emerging themes within the cases. The four main areas of structuration theory have been used as secondary headings to organise each case analysis.

Each of the participants have been given a pseudonym, selected by the researcher, and supporting evidence has been referred to in the following ways:

> HCPs – given a pseudonym

> Support person – referred to in the context of their relationship to the participant (mum, partner, wife)

> Diary Extract – Diary extract

> Pilot evidence – Participants given a pseudonym

It should be noted that some case analyses are shorter in analytical content than others. Although all participants were interviewed for roughly the same length of time, some interviews contained non-relevant information and a significant amount of descriptive content around the process of self-monitoring that was not pertinent to the analysis.

Each case is described below.

Case 1

This case comprised the participant, who has been named Michelle, and her mother. Michelle is a single, 19-year-old university student who has type 1 diabetes and was diagnosed at the age of 10 years. Her mother is her identified support person. Her identified HCP was her practice nurse, who did not return the participation form, and Michelle did not return the patient diary, therefore this case consists of two elements.

Internal structures

The internal structures most relevant to this case were Michelle's engagement with diabetes education and her understanding and awareness. Both Michelle and her mother give the impression of having a good understanding of the condition and self-management and they attributed this to the length of time that Michelle has lived with the condition. However, this high level of understanding that they both alluded to was not demonstrated in Michelle's ability to self-manage her condition. In addition, Michelle's mother talks about a need to gain a better understanding of how to support her daughter to gain better control to better manage her condition, as well as the long-term consequences of her poor control.

Both Michelle and her mother talk fondly about the education provided during childhood when Michelle was first diagnosed. However, later experiences of diabetes education have been more problematic for Michelle, with both referring to a course that she attended as a high school student, where all other attendees were older adults.

> *Actually, no they were all a bit older, well I was the only one there that was in high school.* (Michelle)

They refer to Michelle's discomfort in attending this group. She was later offered another course which was deemed more suitable for younger people, by which point she had reached the age of 18 which was the cutoff age, and she was therefore unable to attend due to being too old.

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> *There was one they spoke about at the last clinic but it was for under 18s and they were like, "Oh well, you're not under 18, so," so.*
> *(Michelle)*

It seems that strict criteria for courses and a lack of matching similar individuals may be affecting educational experiences. It may be that individual assessment of patients with diabetes educational needs and structuring groups of similar needs, with some degree of flexibility, may encourage participant attendance.

Michelle's reluctance to attend the education programme seems to be associated with a fear of having to disclose her blood glucose results. She uses interesting terminology when describing her blood glucose readings, calling them 'scores', a term normally linked to exams or tests, which an individual will either pass or fail. She appears to fear being judged for the 'scores' that she achieves.

Although Michelle does not feel comfortable with the thought of being within a diabetes peer group, she refers to a situation when she was forced to move out of her comfort zone and attended a group education session. Although the group was not ideal in terms of her being matched with similar peers, she explains how this forum, where blood glucose levels were discussed, allowed her to realise that she is not alone in terms of struggling to maintain glycemic control and this appeared to give her some comfort.

> *I didn't want to compare my results with everyone else's, I didn't want to feel that I was doing worse than everyone else, you don't want to feel like you are the only one that can't, which is not the case because there are loads of people in the same boat.*   *(Michelle)*

Michelle speaks about how her blood glucose levels tend to run higher than the desired upper limits and that she has been hospitalised twice for Diabetes Ketoacidosis (DKA). Her mother also reflects on this and feels this is because she does not recognise the signs of her blood glucose level being too high, saying:

> *Her signs when she's too high, em … almost come too late, so she's been consistently high.*   *(Michelle's mum).*

Her mum explains that Michelle has a fear of low blood glucose levels, which stems from having some very unpleasant 'hypos', when she was younger. Her mother feels that it is this fear which influences her to keep her blood glucose levels too high.

> *She had a couple of lows when she was younger and she's really very scared of going into having a low, so she'll tend to ... be cautious on the adjusting, rather than aggressive, em because she doesn't want to get the lows and she's not ... she doesn't have, really that many lows at all, probably not the number of lows that most diabetics have … probably because of that.* (Michelle's mum)

Here, Michelle's mother appears to be justifying and excusing her daughter's glycemic control for not being within normal limits. She may be seeking to find a reason for her daughter behaving in the way she does with her control.

Michelle herself has some awareness of risks but does not demonstrate obvious concern in relation to this. On the other hand, her mother refers to worrying about the long-term risks of her poor control. She feels that, by not testing enough, her daughter is putting herself at risk of long-term complications. She also feels that HCPs do not adequately reinforce the risk of long-term complications.

> *I certainly think they could reinforce a lot more at her age now, em the effects of being too high, the long-term effects … they need to say more: this will happen to you, and they just don't.*
> (Michelle's mum)

Michelle's mum talks about supporting her daughter over her childhood years, which appears to have been a big part of her life. She then goes on to explain how she struggled when her daughter moved into adulthood and she was then, quite abruptly, no longer involved in her daughter's diabetes management. Several times she refers to the frustration she experienced when her daughter moved from child to adult services and her support role ended. She feels there needs to be a level of continued involvement from supporters, especially when the individual with diabetes continues to live within the family home.

> *Part of the issue I have I guess is that when children move out of children's care into over-16s em you're not allowed to come in … but*

> *I'm not at the sessions anymore, I can't do guidance anymore and I can't have those conversations with the consultants who are not giving her the support, the strong support that she needs.*
> *(Michelle's mum)*

She does, however, note that her daughter has chosen not to involve her. Michelle herself does not make much comment on this.

Both Michelle and her mum identify routine and stability in daily life as a facilitator to testing, explaining that Michelle's attention to testing appears to fall away when she is at university and living away from home. Again, this may be an attempt to excuse Michelle's self-management and associated poor control.

> *… but it's more like … it's almost like cast aside in your mind when you are busy with other things. Cause, it's sort of … especially when it's like at University term time and things likes that, it's worse because I'm doing things and I'm forgetting or I'm forgetting to take it with me when I go out and things like that so then, then it turns out everything else falls away (giggle).*   *(Michelle)*

Michelle and her mum both identify many barriers to her self-monitoring. Many, as noted previously are related to the changes which occurred as Michelle was moving into adolescence. She discusses the change from Michelle's regular habits around testing, which occurred at this time. For example, when she moved from primary school to secondary school, she was no longer provided with an area to test or allowed to have a friend accompany her when testing, which had previously been facilitated in primary school.

> *Eventually it was arranged for her to test in the disabled toilet. She was then not allowed to carry her own testing equipment and had to be observed by a school nurse to do a procedure, which she had been doing for many years independently. (Michelle's mum)*

Michelle's mum expresses frustration with the whole process: "it was terrible!"

Being self-conscious regarding testing was also noted to be a barrier to SMBG and again a factor that was associated with the move into adolescence. Michelle herself reports not feeling comfortable about those around her being aware of her testing. Her mum noted that during this time of transition into

adolescence Michelle also developed a desire not to be medicalised or have her condition take over her life

> *… because of this whole thing of not wanting to identify with it … or … you know …* (Michelle's mum)

External Structures

External structures most relevant to this case were Michelle's engagement with health services and supporters.

Michelle talks negatively about hospital reviews and check-ups, stating: "but every time you go you feel like it's a sort of test, that you've got to pass it". However, Michelle feels that she was unable to pass these tests and was thus left with feelings of failure. This again links back to Michelle referring to her results as scores. It appears that she views her management of her condition as something which is assessed, an assessment in which she is unable to achieve well.

Michelle's mum then goes on to talk about how Michelle started to disengage with her condition and with health services and put this down to negative experiences they had both experienced around this time from health services. One such example, was that of receiving conflicting advice from different health services/health professionals: Michelle was advised not to go to her GP with a certain issue and to go to the "Minor Ailments service" instead. However, when she did contact minor ailments she was told that they do not deal with patients with diabetes and to go back to her GP.

> *… and they said, 'Look, don't phone the doctors just go to minor ailments,' so you phone minor ailments and minor ailments won't touch diabetics, so you sort of think, em ...* (Michelle's mum)

Furthermore, Michelle's mum feels that reviews are now a "tick-box" exercise, and that it is this negative, non-collaborative experience which deters engagement.

> *So basically it's just a whole tick, a tick-box exercise, they're in for 5 minutes; 'How are you?', 'Fine,' and then they're out again ... erm ...*

> *so it's a total, total disaster ... she tries to get out of the consultation appointments as quick as she can.* (Michelle's Mum)

Michelle's disengagement appears to be influenced by HCP interactions. As well as viewing interactions during reviews as intimidating due to feeling she cannot pass what she views as a test, she also sometimes feels patronised. Her mum refers to an interaction with a dietician, where Michelle was asked very basic questions to test her self-management, which was way below her level of understanding and made her feel patronised.

> *We used to go and see the dietician, you know ... and it was absolutely a waste of time, she took a plate, and put it in front of her and said … now. And ... she is a clever girl … the dietician took a plate out and said 'What's a carbohydrate?' (laugh), you know and it got to point it was happening every single time and then M ... just wouldn't speak she just wouldn't say anything because she felt stupid.* (Michelle's mum)

Her mum feels that this type of interaction is what caused Michelle to put the shutters down and thereafter not engage, and this particular occurrence was at a time was when she needed it most.

Continuing the theme of how interactions with health services are viewed, Michelle's mum also talks about situations where there has been a lack of understanding from health care associated staff and surgery staff with regard to the importance of Michelle obtaining insulin or replacement insulin pens. She notes that in such situations it has usually been pharmacists who have been most understanding and helpful. Although she told how she feels that sometimes HCPs and health services are not approaching patients in a way that encourages engagement with their diabetes and health services, there is also a feeling that there is not a lot that they, as service users, can do about it. She explains:

> *Well, you can't fight with doctors can you?* (Michelle's mum)

By using a 'battle' metaphor, she may be suggesting that this is how she sees her and her daughter's relationship with HCPs; that they are having to battle

against what is imposed. Therefore, there is a view that there is no option but to conform.

Although Michelle does not view her diabetes reviews as a positive experience, she does conform by attending the reviews. Nevertheless, her mum observes that her daughter tries to get the experience over with as quickly as possible. This gives the impression that there is a feeling of discomfort during this process, which may be due to Michelle's awareness that HCPs recognise that she is not adhering to SMBG practices as she should be:

> *They know my reputation with testing.*   *(Michelle)*

This suggests that Michelle classifies herself as a bad patient and as non-conforming. Yet Michelle is also aware that HCPs are trying to work out why she is not doing what she should be in terms of self-monitoring; again, the embarrassed giggle appears in this statement:

> *… (giggle) … um yes they are always trying to find out why, why aren't you testing, is there anything we can do to make testing more of a thing you do, so they are quite good about trying to help you solve this.*   *(Michelle)*

Although both Michelle and her mother report a level of non-engagement with HCPs, Michelle herself feels that they accept how she monitors and the effect this has on her control and with this she seems resigned to the fact that there is no solution to this:

> *Well, really they've got all my history, they've got the fact that my levels tend to run high, so they are not expecting it all to be down at what it's meant to be … so …*   *(Michelle)*

Continuing this idea, Michelle's mum feels that Michelle's poor control and poor attention to testing, which originates back in her transition into adolescence, was rationalised as being normal for this stage by HCPs and demonstrates anger that her non-conformity was almost expected. So, acceptance from HCPs is welcomed by Michelle but angers her mum.

She does appear to have more positive connection with the nurses, and this appears to be related to when there is continuity of care with the same nurse.

Her mum also refers to this when talking about difficulties that have occurred where there is lack of consistency with HCPs, identifying this as a barrier to engagement.

> *Well, it is sometimes like starting at scratch when you get someone new, I don't think they would know anything unless I said. (Michelle)*

Michelle's mum fears that this disengagement, which, in her opinion, occurs in younger adults, may be what is affecting her compliance with self-monitoring and self-management and in turn may increase her daughter's risk of experiencing diabetes-related complications. She also fears that when re-engagement does re-establish, it may be too late, in terms of the damage affecting the risk of complications.

> *I would probably like to know more about the side effects and what to look out for, em ... cos no so much about the diabetes but the side effects what to look out for so I can see, so I can see if anything is going wrong. (Michelle's mum)*

Michelle explains that her goals are set on the higher end of the spectrum due to the awareness from HCPs of her poor control. Again, she welcomes this acceptance from HCPs.

> *… my goal is 10 and not 7, because 7 would be unrealistic for me (giggle), yeah. (Michelle)*

The giggles, which are regularly noted throughout Michelle's interview, give the impression that she is somewhat embarrassed about her level of control and the fact that allowances are made for her, and that even setting goals on the high side are difficult for her to achieve. Her mum concurs, stating that she feels that her daughter's goals are unrealistic and this affects her practices around self-monitoring. This suggests that there may be miscommunication between Michelle and her mum regarding her goals.

> *… but sometimes I do feel that she is so far off that; why should she bother, because she is so far off and she's never going to get there. (Michelle's mum)*

Michelle then goes on to explain what she describes as a simple process of putting this target into her SMBG monitor, and it then works all the necessary self-management actions. Although this is presented as a simple process, she admits to not using her monitor or testing enough, therefore the intention is not there and, in turn, the practice does not happen.

<u>Actions</u>

Actions in this case were in relation to the process of self-monitoring and associated self-management and the influences on this. Michelle gives a sense of not wanting to be controlled. This is noted in her reluctance to involve her mum in her diabetes or to take her advice. Her mum also notes that Michelle avoids learning more about her condition. For example, she will not look at the Diabetes UK literature which is delivered to their house, or take notice of any other diabetes-related information. This is also noted in Michelle's negative view of contact with health services for her diabetes; there appears to be an issue with surveillance for Michelle.

Both Michelle and her mum describe the emotion of frustration that Michelle feels when she is unable to achieve a level of stable blood glucose control. When probing further to see whether Michelle explores patterns or the reasons for her poor control, it appears that Michelle's lack of engagement with her condition prevents her from exploring her control in any detail. Michelle's mum displays emotion due to this vicious cycle and in her concerns regarding the implications of this poor control on her daughter future health.

The impact of living with a chronic condition has had an impact on Michelle's emotional health, as her mum refers to Michelle having visited a psychologist during the difficult adolescent transition years.

When Michelle is asked about the frequency and timing of self-monitoring she does connect the idea that attention to testing is related to improved glycemic control and in the same way relates her poor control to giving less attention to testing.

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> *And you notice in annual reviews and things if you have been doing the tests, probably as you should, your control is like a lot better overall, than if you have not. I mean, I have to say, my control isn't great at all, and I think that is pretty much due to the fact that I don't do a lot of tests.* (Michelle)

She accepts that what she should be doing in terms of the regularity of testing is not what she is doing in practice. She talks about HCPs advising her what to do in term of testing but she rationalises that they understand that this is not always possible, therefore she seems to believe that what HCPs advise is not what they really expect. This may allow her to excuse her non-compliance and lack of self-monitoring, which she refers to.

> *Well … in a ideal world, it should be before every meal and um … something like 2-ish … 2 hours after. But in reality it is not usually anything like that.* (Michelle)

Michelle uses the term 'ideal world' frequently throughout her interviews when alluding to the fact that she does not test as she should and even notes this repetition herself by using the term, "again":

> *Again, in an ideal world it would be to test sort of."* (Michelle).

Michelle's mum also confirms that her daughter does not test anywhere near as often as she should and that her testing is quite ad hoc. She feels this is the reason for her poor control. Michelle affirms this when stating:

> *I think it pretty much due to the fact that I don't do a lot of tests.* (Michelle)

Michelle does not record any of her results but they are all stored in her device, which she takes along to reviews. Her mum explains that her daughter used to document all results and again relates the change in behaviour around recording results as occurring when she moved into adolescence.

As noted previously, Michelle avoids discussing results in detail with HCPs and notes that the only time she looked at patterns was as a child, referring to previous practices:

> *Well, maybe years and years ago, maybe at children's clinic, with*
> *sort of risk control and stuff.* *(Michelle)*

The reference to 'risk control' for children suggests that she appears to consider this unnecessary for adults. It may be that Michelle believes that risks associated with patterns of blood glucose levels are only dangerous to children.

Michelle describes almost casting self-monitoring aside when life is busy, for example, university life. She admits to forgetting about testing and also admits to not considering or facilitating testing at this time and refers to never taking her equipment out with her: "but it's not much good if I don't take the thing with me (giggle, giggle)"..

Although Michelle admits to not paying enough attention to self-monitoring and associated management, she also admits to changing her self-monitoring and self-management behaviours close to the time of clinic reviews.

> *… and then you're like; oh, ok, it's not good, so I should be changing*
> *something. So maybe for a week or two weeks you start to really*
> *kind of focus on testing.* *(Michelle)*

So, although she refers to HCPs being aware that she does not monitor enough and they set higher than expected goals for her, she also admits that HCPs do not have a true picture of her glycemic control due to this change in behaviour before and after clinic reviews. She feels a need to manipulate the situation so it does not look quite as bad as it really is.

Michelle generally explains problem solving in terms of reacting to abnormal readings. She can explain the process of reading results and taking the appropriate actions in theory but admits to this being 'ideal' and, in practice, it may not happen this way. For example, she explains that abnormal results should be rechecked following actions and admits that she rarely remembers to do this and even admits to sometimes forgetting to take the insulin dose she has calculated.

In the same way, Michelle and her mum note that although she may have calculated the correct ratio of carbohydrate intake to insulin, she then does

something different to what she has calculated, which puts her control out, Michelle noting that: "there's nothing wrong with the ratio".

Michelle comes across as an intelligent girl and her mum emphasises this by referring to this being ironic in view of how she applies her intelligence to her self-monitoring:

> *She's a clever girl … that's the irony of it.* (Michelle's mum)

Michelle is aware of and has sampled diabetes-related apps and web-based tools and information but does not engage with new technology to assist with her self-management on a regular basis. It was also noted that small barriers such as a small cost for using an app deterred Michelle from continuing to use such technology. In the same way, Michelle recognises that there are many tools to facilitate self-management which are at her fingertips; the problem is that she does not use them. When talking about this, again, she giggles in a way that suggests she is embarrassed about this.

> *So now, it does that all for me, it's the machine, yeah you put in well your goal, you put in your ratio and your correction ratio[1] and now it does that all for you (giggle) so now the time it takes is nothing compared to the way of how we used to (giggle).* (Michelle)

It was noted that Michelle's self-assessment of her confidence around self-monitoring and associated self-management was low (score 6–7 out of 10). This was attributed to the confusion she sometimes experiences as to why her blood glucose is unstable.

Michelle rates the importance of SMBG high (10 out of 10), referring to it as providing safety for self-management. However, she seems to have difficulty applying this importance to her behaviours around self-monitoring, admitting to not monitoring enough and sometimes forgetting to take important actions following monitoring.

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[1] Here Michelle is referring to the correct amount of carbohydrate intake in relation to the amount of insulin units taken.

<u>Outcomes</u>

Based on what Michelle and her mother report, Michelle's overall control is poor and because of this she has experienced recent acute illnesses which have resulted in DKA, requiring hospital admissions. As well as acute illness, Michelle experiences emotional health problems which have necessitated professional help. In addition to acute hospital admissions, Michelle's mum refers to some physical symptoms which she feels are caused by her daughter's poor control, for example, night sweats.

<u>Key points from Case 1</u>

Michelle has poorly controlled diabetes which appears to affect her overall health. Her own form of decision making, fear of extreme hypoglycemic episodes, leads to her choosing to maintain blood glucose levels higher than recommended so as to avoid hypoglycemic episodes. This is noted to be an important driver for the way that she self-manages her diabetes. She is noted to not want to identify or be controlled by her condition, fearing surveillance from health services and her mum, which appears to push testing and self-management far from her mind. This also appears to influence her poor relationship with HCPs, which is affected by her view that self-monitoring is a scoring system within which she is constantly failing.

Michelle has a fear of peer interaction and sharing information about her glycemic control and self-management. This appears to affect her empowerment and desire for information about diabetes and may be related to her problems with emotional health.

Michelle's mum links many issues that affect her daughter's engagement with her diabetes to the move from child to adult services, which affected her ability to continue supporting her daughter. Her mum also raises other issues with health services: putting too much emphasis on avoiding low blood glucose, not enough awareness of diabetes-related complications, and being provided with conflicting information and advice, as well as a lack of continuity of care.

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Case 2

This case comprises the participant, who has been named Maureen, a female housewife, aged 46 years and diagnosed with type 1 diabetes when she was 10 years old. Maureen identified her husband as her support person and her diabetes consultant as her HCP who has been named 'Dr Hay'. Maureen did not return her diary and therefore this case consists of three elements.

Internal structures

The internal structures relevant to this case relate to Maureen's skills and understanding stemming from her length of time living with her diabetes. As in the previous case, Maureen and her husband both consider themselves to have a high level of understanding in relation to her diabetes due to the length of time she has lived with the condition.

> *I think after 30-odd years of them living with the condition, you're not going to tell them how to suck eggs or anything like that.*
> *(Maureen's husband)*

This perceived expertise instills a view that there is no need to seek further understanding, regardless of successes with self-management and associated glycemic control.

> *Well, I've been doing it for so long, so I know what to do. I think some courses have been mentioned a couple of times over the years, but I've not really needed to …* *(Maureen)*

Although Maureen's husband feels his wife has a good understanding of her condition, when discussing a course she is due to attend regarding a change in therapy, he refers to the fact that she has been a stay-at-home mum and out of employment for many years and therefore he should attend the course with her. He seems to question her ability to take on new information and skills. This is something he refers to several times during the interview.

Maureen's focus and overall rationale is on preventing her blood glucose level from dropping too low, as she has recently experienced several hypoglycaemic episodes, and has subsequently lost her driving licence. She also refers to

having a higher awareness through physical symptoms of low blood glucose as opposed to levels being higher than normal, which may also be a reason for her focus on preventing levels from dropping too low.

Maureen's husband has a high level of involvement in her diabetes management; he attends reviews with her and also logs her SMBG results on a spreadsheet. This is something that has continued for a number of years.

> *Well, every clinic visit … I've been going with my wife, and just um ... there's many things going on, to monitor that many different things, as there is a lot of diabetes things, then it just helps to have an extra set of ears to try and take things in and eh for understanding, help me understand as well, what's going on ... (Maureen's husband)*

In addition, he is keen to be involved in any education she attends in relation to her self-management. He gives the impression that she may not be able to fully understand due to her length of time out of employment.

> *My wife's got this course coming up in July and I think if I could attend, but I don't think I can, then I think that certainly if em it was available to me to help my wife out as well, because sometimes these things are, especially for my wife who does, well she's never been in employment for 16 years so she's out of that you know, out of the way of technology and things, so sometimes having an extra pair of ears, ken, because I've, might help, might help – putting things in a bit more 'layman's terms' … yeah, yeah.*
> *(Maureen's husband)*

Maureen does not identify any barriers to testing. She refers to testing wherever she is; at home or out and about, and she demonstrates effort and forward thinking to facilitate testing, for example, she explains how she overcomes some problems around testing by carrying a bag to house her testing equipment. She admits to being a little self-conscious and not wishing to draw attention to testing when out.

> *Well, if I'm out I must admit, I've got quite a big handbag, so I do it in my handbag bit, like, I do feel a bit, I wouldna like people to know what I'm doing, and it shouldn't really be like that, no, but ... but I must admit, I tend to do it in my bag if I can, because I don't really want people seeing what I'm doing. (Maureen)*

<u>External structures</u>

External factors for this case relate to Maureen's support from her husband, her relationship with health services, and her associated outlook on her condition. Maureen and her husband at first sight appear to have a positive view of her encounters with health services and she appears to engage with her diabetes and health service. There appears to be a positive attitude from both in terms of how she is managed and how she is able to access additional help and information.

Maureen refers to taking her completed spreadsheets along to the hospital diabetes review with the consultant but does not consider discussing her control with any other HCP:

> *No, no, I only show it to him (referring to the hospital consultant) …*
> *Because nobody else ever asks for it.* (Maureen)

When asked about GP visits, she responds: "No, he wouldn't want to see them" (Maureen).

Here there is a contradiction in her initial positive view of health services' interest in her condition or expertise in assessing her diabetes.

<u>Actions</u>

Actions relating to this case relate to Maureen's routine approach to testing and associated management. Maureen tests regularly and appears to generally take actions on results. In addition to this, she appears to consider what she is doing over the rest of the day and pays attention to the differing blood glucose levels she gets.

Testing is frequent, around 3–4 times per day routinely, with additional tests for physical symptoms, which can be up to 10 times per day.

Although Maureen pays lots of attention to testing, she does experience episodes of poor control, usually low blood glucose. She finds this particularly frustrating and confusing, as she feels she is very careful with her testing and associated management.

> *You know, I'm getting no results that are ... you know ... for what I'm doing I feel I should be feeling better, but I'm no … because there's other things happening that's make the levels low.* (Maureen)

Maureen does seem to problem-solve her results and associated management, to a limited degree. She considers adjusting treatment in relation to blood glucose levels and considers future energy requirements over the rest of the day.

When asked about using new technology to assist with her diabetes self-management, she reiterates what her husband has said about her being at home and out of the workforce for many years. She seems to have the same belief as her husband that using technology is beyond her capability and this appears to affect her confidence in her ability to learn new things.

> *I haven't worked for 20 years since I had my family and I can't use computers and all that. My daughters know how to use all that and I suppose they could help me if I needed to do anything, but I don't have anything like that.* (Maureen)

It is interesting that although both Maureen and her husband consider her not to be computer literate, later in the interview she refers to using an iPad regularly. She does not relate this to her ability to use new technology and so having a level of computer literacy. This lack of belief in her ability to use technology may have been influenced by her husband's opinion in relation to being out of the workforce.

> *My wife's no really conscious of, I mean … she's no worked for 16 years so, um her experience of computers is really the iPad and this is just a case of very limited, no that of, well people in employment use computers all the time you know ...* (Maureen's husband)

Although Maureen considers her blood glucose levels over the course of the day and her results are logged on a spreadsheet, it is actually her husband who is logging them and therefore looking at them in the longer term.

> *Well, my husband does it all and has some fun with it actually, it's like a graph almost, and it's got before breakfast and after breakfast and things like that, and dates so he sort of fills that in.* (Maureen)

In addition to this, Maureen's husband feels that it is the doctor's job to look at the results and patterns, suggesting that he logs all of the results on spreadsheets for medical staff, without really considering that Maureen herself may be able to analyse the readings.

> *To be fair to my wife, she'll look herself and say it's been really high for the last 2 or 3 days or it's been really quite low em ... but I wouldn't analyse it the way ... the doctor does in any shape or form.*
> *(Maureen's husband)*

This may also originate from the historic tradition of the doctor being the expert and the patient not possessing any knowledge.

Although Maureen has significant involvement and support from her partner, it is evident that such support may not always be empowering to the individual when the support undermines their ability to understand and apply various self-management methods and analysis.

This may be one of the reasons that Maureen rates her confidence level low; at 6–7. She has recently experienced a period of glucose instability, which has made her less confident in self-monitoring and associated self-management. Therefore, the lack of belief in her ability, along with her inability to effectively control her blood glucose, has affected her overall confidence.

> *The last year, I've been having a lot of problems due to my diabetes, so I don't feel as confident as I did before.* *(Maureen)*

Maureen has recently lost her driving licence due to her low blood glucose levels. This has further affected her confidence and her independence. She is now dependent on her husband for transport.

> *I had actually been having a lot of lows, so sort of, so I've not got my licence the now … So I can't get about the same … I wait for my husband to get back.* *(Maureen)*

As noted previously, Maureen's diabetes reviews are generally seen as a positive experience, although, as in the previous case, Maureen's husband does make reference to a lack of continuity of HCP and suggests that it would be helpful to have a designated person overseeing his wife's diabetes.

Maureen recognises the importance of SMBG, rating it 7–8, slightly higher than her confidence. However, this was not as high as many other participants rated importance. This may be related to her husband's view of self-monitoring importance. Her husband did not rate SMBG highly, noting that it was not a critical part of self-management.

> *I mean in the grand scheme of things, to me testing your blood is not that critical, I mean there's other issues at stake you know.*
> *(Maureen's husband)*

He describes it as a means to an end, something that has to be done four to five times per day. He does not seem to see its place in relation to problem solving his wife's fluctuations in glycemic levels.

Outcomes

Outcomes relevant to this case are related to Maureen's tight control, which results in frequent low blood glucose levels affecting her ability to drive. Although Maureen works hard with her self-management she continues to experience hypoglycemic episodes which have had an impact on her confidence and independence through loss of her driving licence. It may be that her husband's strong input and influences through logging her results on a spreadsheet and attending her reviews, may be somewhat controlling and disempowering and may be encouraging her to keep control too tight, which is resulting in regular hypoglycemic episodes.

Key points from case 2

Maureen has experienced poor glycemic control for some time, specifically glycemic levels dropping too low. She does self-monitor regularly on a routine basis and in response to physical symptoms of low blood glucose, and does show some signs of problem solving over the day, but analytical thinking around her results is limited.

Her poor control and loss of driving licence have affected her confidence and independence, which may in turn affect self-efficacy and empowerment, noted

in her lack of self-confidence around using new tools to assist with her self-management.

Maureen's husband's role in her diabetes is important in terms of how his involvement may be influencing her ability to feel empowered generally and in her self-management.

Case 3

This case comprises the participant, who has been given the name Angus, a male retired university lecturer, aged 75 years. He was diagnosed with type 1 diabetes when he was 57 years old. He identified his wife as his support person, who consented to participate, and his practice nurse as his identified HCP, who did not return the participation form. Angus did return the patient diary and therefore has two forms of supporting data.

<u>Internal structures</u>

Internal structures relevant to this case relate to Angus considering himself to have a good level of knowledge and understanding about his diabetes. This is attributed to his background in education and he refers regularly to his experiences of educating students.

> *I know ... the principles behind self-monitoring, because I actually encouraged the students to do a project on that, so, which was the gathering the data.* *(Angus)*

However, on deeper exploration, his understanding centres around how to deal reactively to low blood glucose levels and he appears to have little knowledge around how to deal with high blood glucose levels.

Angus and his wife have never been offered any formal education that involves self-monitoring. His wife feels they would both benefit from further education, as they only education she has had was being given leaflets at the outset of his diagnosis, which she feels were too broad and not specific enough in terms of the practicalities of meal ideas and health outcomes, emergency situations, and complications. She refers to how she struggled with working out dietary requirements for her husband.

> *I think when they told us that diet was so important, I really struggled with that because they said you know, you eat a normal diet as much as possible, but you know; I would have liked at least for somebody to have said; here's a good diet that you would go onto for 2 weeks, and then you know, get into habits like that, and then use that as, like a basis for future eating habits. But actually it was all too varying, and I did struggle with that.*   *(Angus's wife)*

Angus's main concern in terms of glycemic instability is around having low blood glucose levels when he is travelling, and because of this concern he admits to keeping his levels higher than recommended at these times.

> *… like at least 2 points higher than usual, it's, it's sort of, if you like a self-protected mechanism, that I'm making sure that I don't drop on the drive down.*   *(Angus)*

He does suggest that it is not unusual for his blood glucose levels to be at a higher than normal level, as he talks about the relief he experiences when he realises his level is not too high: *"oh … phew … you're not too high"* (Angus).

Angus talks about being confident in dealing with high blood glucose levels but not low levels. He appears to be comfortable with increasing his carbohydrate intake but not with adjusting his insulin dose. This may be the reason he is regularly experiencing blood glucose levels higher than recommended.

His wife appears to be involved in his self-management to a certain level and she talks about going to some reviews with him and how they sometimes discuss abnormal blood glucose levels to try and work out why. However, there is some resistance from Angus himself to her involvement; he refers to her comments about his diet and how he does not listen or pay attention.

> *My wife would quite frequently say to me that you're having too much carbohydrate and you shouldn't take porridge and toast at breakfast, you should take maybe toast and fruit or whatever, but I tend not to ... not to listen to that.*   *(Angus)*

His wife also states that she no longer goes to reviews with him; she may have picked up on this resistance to her involvement.

Again, Angus describes the physical symptoms of low blood glucose but does not mention experiencing any feelings of his blood glucose being too high.

As well as identifying a need for more information, noted in the education section, Angus's wife also notes that she is not confident in testing his blood glucose, should Angus be unable to do this for himself.

Angus sees SMBG as facilitating many lifestyle acts and allowing him to manage his life and maintaining a level of control. He talks about how he is able to play golf and drive because of SMBG. So by testing he is given permission to partake in these activities.

> *… because if I didn't get it right then … if I want to play golf, if I want to drive the car, or if I want to climb a hill … I can be up the creek.*
> *(Angus)*

Angus notes barriers to testing; firstly, the difficulty in testing and then problem solving the necessary actions; and then when he is out socially, sometimes he forgets to take all the necessary equipment. This can then result in a period of glycemic instability, which he then finds difficult to manage following the social event. This he finds very frustrating: "… at times it's a real inconvenience" (Angus). He describes doing something different in his daily routine as having a: "crazy effect" (Angus).

The second barrier to testing he notes is the repetitive nature of the process, which is as painful in monotony as the pain of the invasive procedure. He describes it as a "chore" and describes how the chronic nature of the condition, with no prospect of end to self-monitoring, can get him down.

> *But em there are specific times I do get like … I do say, 'Oh crap, why do I have to do this?' … I do think, 'What is the point in this?' It's a hassle, you have to break off, irrespective of who's here and go and do it.*
> *(Angus)*

External structures

External structures related to Angus are linked to his attitude to his wife as a supporter and to health services. Angus's wife refers to the lack of knowledge and expertise around diabetes from hospital staff whose remit is not diabetes. She gives an example of when Angus was admitted unwell with a high

temperature to emergency, at which point his blood glucose level was extremely high. When she questioned this she was told:

> *Oh ,just carry on as normal, just think as if you were at home normally and what you would do, think as if you were at home and not here … but we weren't at home, and this wasn't normal, he was ill and it changes everything.*   *(Angus's wife)*

His reviews are at the hospital clinic, when his main interaction is with the diabetes nurse. He feels his interaction with the doctor during these visits is a tick-box exercise.

> *The regular … em … clinic sessions have been really just to tick boxes, take your blood to send it away, well … .nice to see you ... see you again in 6 months.*   *(Angus)*

Angus also refers to an impersonal approach demonstrated by some HCPs, and gives the example of meeting one of his GPs at the hospital clinic and how the GP did not refer to having dealt with him previously.

> *... one of the GPs who was actually the first person I met when I was referred to the hospital was actually doing ah a specialism in diabetes, and he appeared like he didn't recognise me … you know … when I subsequently went to the clinic, he didn't even refer to the fact, so ... and I was actually rather ... disappointed by this.*
> *(Angus)*

When asked about goals, he talks about once discussing this with a nurse but he did nothing about it as he considers himself too old.

> *So I'm not really interested in setting goals on a weekly or a monthly basis, so I mean that's out as far as I'm concerned, I'm too long in the tooth to do that. (laugh)… the specialist nurse, she did try to em ... encourage me to be more accurate in, like for example my carbohydrate intake, and she suggested that over a fortnight that I would sort of monitor it and then, you know set targets; but no, I was, I just wasn't interested.*   *(Angus)*

He appears write off the prospect of making any positive changes in his diabetes management.

Actions

The actions in this case relate to how Angus's knowledge and skills linked to his self-monitoring and his ability to maintain blood glucose at a stable level. Angus self-monitors fairly frequently throughout the day on a routine basis and in relation to physical symptoms.

> *It's em ... very much in on the first hand, it's a routine, it's got to be done, when I wake up in the morning or whatever but there are the ... eh ... particular occasions when I ... I'm aware of the fact that, of how I'm feeling subjectively and I'm not quite right and I'll take the monitor with me.* *(Angus)*

Actions for Angus are immediate after testing: documenting the result and considering his food intake in the short term in relation to this result. There is little forward planning over the rest of the day.

Angus demonstrates the emotion of frustration throughout the interview regarding the difficulties and confusion in trying to maintain glycemic control. This emotion is also noted in his diary extract when he tests at the end of the day and discovers that levels are significantly high and he describes feeling *"disappointed"*.

Angus's testing is generally undertaken routinely and when he feels physical symptoms of low blood glucose. He notes that he has never been advised by an HCP how often he should test; his practices have developed through experience.

Both Angus and his wife describe how he reacts to problems as they occur rather than observing the fluctuations over a period of time.

Angus relates periods of improvement in his control with paying more attention to self-monitoring. This is also described in his diary extracts where he tests and then adjusts the next meal accordingly.

He describes the physical signs of low blood glucose but makes no reference to the signs of blood glucose levels being high. His wife also notes this:

> *… and if the level is high, there is not really much other than
> tiredness.*   *(Angus's wife)*

Outcomes

Outcomes in this case relate to how Angus's perceived knowledge and skills
were translated in his overall control and his perception of how this may affect
him in the future. Angus recognises how SMBG assists with his quality of life
by allowing him to drive and undertake social activities, such as golf, with
confidence. However, because he has not so far encountered any diabetes-
related complications, he views himself as not being at risk.

> *I can't see it affecting my vision much, can't see it affecting my
> circulation in terms of the time I have left, I can't see some disastrous
> effects on me, well I hope so …*   *(Angus)*

Therefore, outcomes for Angus in terms of his self-monitoring are related to the
short-term management of his lifestyle.

Key points from case 3

Angus tests regularly and takes immediate actions and his wife plays a limited
to moderate part in supporting his diabetes. He demonstrates a desire not to
be controlled by his condition and a fear about losing this control. He is
frustrated by the chronic nature of diabetes but appreciates the control that self-
monitoring gives him to partake in the activities he enjoys.

This participant is educated to a high academic level and is therefore a startling
example of someone who is not getting it right with applying SMBG to his
diabetes self-management despite an evident ability to research, read and
absorb information. This raises the question about why this is so difficult to
understand and get right. Is there something wrong with the self-management
education being provided?

Case 4

This case comprises the participant, who has been named Tam, a 68-year-old
retired non-professional, diagnosed with insulin-treated type 2 diabetes seven

years ago. He identified his partner as his support person, who agreed to participate, and his practice nurse as his HCP, who did not return the consent to participate form. Tam also returned his patient diary and therefore has two forms of supporting evidence.

<u>Internal structures</u>

Internal structures for this case are related to Tam demonstrating limited understanding of diabetes and diabetes self-management; for example, normal blood glucose levels, how much above and below this he should allow his levels to fluctuate, and the importance of this. When he is asked about the risks of blood glucose levels being too high or too low, he refers only to hypoglycaemic episodes.

Tam's partner's understanding is on a similarly low level to his own.

Tam cannot remember having any formal education since being diagnosed with diabetes. His understanding appears to have been generated from HCPs advising him on how to react to abnormal results.

> *Somebody said along the lines … get glucose ... eh … incase I took a hypo … aye ... when I went to see them, they telt me to get glucose.*　　　　　　　　　　　　　　　　　　　　*(Tam)*

Although Tam has poor understanding, which is reflected in how he manages his condition, he does not see the need to make moves to learn more.

> *I don't think I would really like to go into more depth about it. (Tam)*

He also does not see the benefit in talking to others with diabetes and seems to want to dissociate from it.

> *I mean I know a couple of people that are diabetic and I dinnae go and talk about it, you know, I don't think I would benefit really, I don't think it would benefit me.*　　　　　　　　　　　　　　*(Tam)*

Tam's partner expressed a need for education, especially in relation to emergency situations. She talks about the fear of having to assist her partner in such situations previously and describing it as: "em, it's just a bit scary"

(Tam's partner). These words suggest that his partner is worried about the prospect of an acute medical episode occurring again which she may have to deal with.

Tam has little concern about blood glucose levels reaching levels higher than the recommended limits, but does denote fear at the prospect of levels dropping too low and uses terminology similar to that of his partner:

> *I'm more frightened about it going doon than I am about going high.*
> *(Tam)*

This focuses his attention on avoiding blood glucose levels dropping low to avoid hypoglycemic episodes.

This was also noted through discussion with Tam about how he manages his diabetes and also through his diary extracts.

> *Level 12.9, to see the difference, did nothing*
>
> *Level was 20.0 so did nothing*
>
> *Level was 24.0 did nothing*
>
> *(Tam diary extract)*

These are dangerously high blood glucose levels, well above the upper recommended limits, and Tam does nothing because he is focused on avoiding a hypoglycemic episode which requires immediate emergency medical care.

His partner also notes that he will make reference after testing to a result being too low but never to it being too high.

> *Well actually, that again, I mean I've heard him saying, "Oh, it's too low,' like I've heard him saying it's too low, but I've never heard him saying it's too high.* *(Tam's partner)*

Tam describes the physical feelings of blood glucose levels dropping but makes no reference to any physical symptom when blood glucose levels go too high.

> *Well, I've had a hypo once and it was low … I've never had anything eh, when it's been high … but if it's too low, you know it's too low,*

> *you can feel it … but as I've said, if it's gone high, even up to 30, I*
> *don't feel any different.*   *(Tam)*

However, Tam does know about the long-term risks associated with diabetes:

> *It can affect your heart … some people end up with amputations*
> *because it affects your circulation.*   *(Tam)*

He does not link these risks to poor control and running levels far above those recommended. There is an understanding of risks being associated with not managing your diabetes appropriately, but he does not seem to join all of these points together and also only seems to consider risks in the short term related to low blood glucose levels.

Tam's partner also talks about the acute dangers associated with a hypoglycemic episode and does not refer to any long-term risks or the association between high blood glucose and risks, even when asked directly about blood glucose levels going too high, she admits: "Well, I can't really, no, I don't really know" (Tam's partner). So, although Tam has some knowledge about the long-term risks, this information has not been discussed with his partner.

Tam's reason for testing is to present results to HCPs, allowing them to see fluctuations in levels: "It's… for the nurse … to see variation" (Tam). Therefore, he views self-monitoring as a stand-alone task and not part of his overall self-management.

Tam rates self-monitoring low in term of importance: 7–8. On the other hand, he rated his confidence in self-monitoring higher; at 9. It is interesting that he does not link his very poor control with his self-monitoring and associated self-management and appears to completely remove any personal responsibility.

Tam's partner appears to have very little involvement in his management other than having to assist him during acute hypoglycemic incidents.

Actions

As Tam had limited knowledge and skills, he had little to draw on in terms of actions. Tam views self-monitoring as something that allows you to see what is happening and take action when necessary but does not really engage with the concept of self-management. He describes this as being 'halfway in control', then goes on to explain that he does not conform to what is recommended.

> *Well, self-monitoring is so's that you can be halfway in control of what you see … I mean, I'm supposed to stick to diets and I stick to it a bit but I dinnae really follow it, I don't follow it right through, I mean I have chips and things and I have sweeties, which I know you're not supposed to dee, eh ...*   *(Tam)*

Actions are taken generally in relation to low blood glucose levels. Tam does not consider high blood glucose levels as requiring actions.

> *... so actions that I take, I dinnae take any actions, eh, other than, if I feel low or if it is low, I'll go and get, I've got glucose eh tubes in the house, I'll go take a glucose tube, but if it's high I don't do anything, there's not much I can do, eh, there's nothing you can dae, you cannae take glucose for it because it's high anyway so.   (Tam)*

When asked about insulin adjustment, he refers to HCPs making changes to his insulin regime and does not consider this as forming part of his self-management.

Tam also admits to sometimes forgetting to take the required actions in relation to his diabetes self-management. His partner also refers to reacting to low blood glucose levels, explaining where in his house she can find emergency glucose supplies.

Testing for Tam appears to be at irregular points throughout the day and also when he feels signs of low blood glucose but also confesses to often putting off testing and he sees no problem with this.

> *You say, ah … I'll dee it later, so you delay it till later in the day be fine, so I don't really have a problem with self-monitoring at all.*
> *(Tam)*

Tam does not always record his results and the barrier to him recording his results seems to be having enough pages in his diary. He generally keeps pages free and starts testing and recording prior to a clinic visit. He does not seem to consider recording results anywhere other than in the self-monitoring diary.

> *... I would like to get at least the last page going up to the hospital at the time, you know, at a time ... you know, it has been lately, right, when it's relatively full up and then I've no got a diary left, because they are difficult to get, well I'm not saying it's difficult to get them but I don't know ... every time I go up, I ask for a diary because it's year ...* (Tam)

Tam refers to his control as being 'halfway in control'. On deeper exploration, Tam is of the view that there is only so much he himself can do to assist with his control and the rest is outwith his control. This appears to be how he justifies his poor control, by removing the personal responsibility.

Tam has an active social life and is out most days meeting friends in the pub. He would never consider taking his equipment and testing while out. This appears to be partly down to not wanting to draw attention to his condition as he talks about not discussing his diabetes and not feeling comfortable testing when out.

Tam demonstrates little problem solving and does not appear to consider why his results are not stable or how he could avoid this.

> *... you're too high, but what do you do ... eh ... well there's nothing you can do after it tells you ... it's already there, right.* (Tam)

When he says he is already there, he does not seem to consider how he could avoid getting there.

Tam is aware that his lifestyle behaviours of going to the pub, alcohol intake and poor diet is an area that HCPs are not happy with. However, he does not consider this to be an area he can address and accepts the situation.

External structures

External structures relate to how Tam engaged with health services, support people and peers. Tam is reviewed annually by the hospital and annually by the GP and this sometimes falls at a similar time and he can therefore at times go for nearly a year between reviews.

> *... well it's supposed to be a year, sometimes it's quite a bit over a year, aye ... it depends, if they cancel ... eh ... it can be ... it was cancelled the last time and the practice nurse asked, she asked me to ask when I ... and I said, 'I think it's been well over a year since I've been up.'* (Tam)

Tam's partner feels that he is "needing to be at the doctor's more" but acknowledges that Tam himself would not be keen for more reviews.

Although Tam has been given a broad range of levels that he should aim to keep his blood glucose between, it does not seem to concern him too much when his levels fluctuate far beyond these levels.

He considers that the HCP's goals for him are to address his lifestyle (drinking and poor diet).

Outcomes

Tam's immediate and longer-term control is very poor and he and his partner refer to episodes of acute hypoglycemia which have required emergency services. Tam relates quality of life with the ability to continue his previous lifestyle habits and does not appear to consider how poor diabetes control could ultimately affect his quality of life.

Key points from case 4

Tam has been diagnosed for a relatively short period of time, but his understanding of self-managing and demonstrated practices are particularly poor, which results in him experiencing extreme fluctuations in glycemic control. Lifestyle factors also appear to play a significant role in his poor diabetes control. Although Tam is aware of how his lifestyle practices and how he manages his condition are affecting his level of control, he refers to not being

able to do much about this. He also talks about not wanting to discuss his diabetes too much. This all appears to absolve him of personal responsibility in relation to his diabetes and demonstrates some level of denial in relation to the consequences of his condition.

Case 5

This case comprises the participant, who has been named Brian, a retired non-professional aged 65, who has been diagnosed with type 1 diabetes since his early twenties. He identified his female partner as his support person, who agreed to participate, his podiatrist as his HCP (an extended scope diabetes specialist podiatrist), who also participated and has been named 'Podiatrist Colin'. Brian also returned his patient diary and therefore this case includes all forms of supporting evidence.

Internal structures

Internal structures for this case relate to how Brian had generated his knowledge and practices in relation to self-monitoring. Brian viewed his length of time living with his condition as qualifying him in knowledge and understanding around managing and monitoring his diabetes.

> *Look, I've had this for over 40 years, I've had to live with it for over 40 years.*   *(Brian)*

Although he has lived with diabetes for a long time, he only started self-monitoring around five years ago, following a severe hypoglycemic episode. Brian demonstrates a strong sense of not wanting to be different and to live his life normally and refers to the time previous to commencing self-monitoring as:

> *Because I lived a very normal life, apart from having to take the injections and realising that I have to eat 3 meals and maybe a drop of supper if I felt I showed signs of hypos.*   *(Brian)*

Brian's support person does not appear to be very involved in his diabetes and does not have a great understanding of diabetes, mentioning wrongly that high blood glucose could give you a hypo, and also giving higher than normal goal values.

> *Well I reckon they need to get about say 10, 11, 12, 13 is about right,*
> *if it's going any higher than that, you've got to be very careful eh, or*
> *lower.*
>
> *When the level is high, that's when they can take a hypo, and I think*
> *they can actually just blank out and that.*   *(Brian's partner)*

She also has a fear of Brian having an acute hypoglycaemic episode, noting that she does not feel knowledgeable enough in what to do.

> *I'm always quite frightened in case he actually takes a hypo and I*
> *wouldna ... all I know, all I know then was to give him a glucose*
> *tablet and it's quite scary stuff, but I never ever experienced that so*
> *I'm quite fortunate.*   *(Brian's partner)*

Brian could not recall attending or being offered any formal education, learning to self-manage over the years from information and advice offered during consultations.

It appears that, prior to his severe hypoglycemic episode, prior to commencement of testing, Brian had not been educated in SMBG. When asked about education, he recalls a situation when the impact of diabetes most hit home with him: after his diagnosis he was taken by a doctor to a ward full of patients with diabetes-related complications, who looked extremely ill; this really shocked him into taking the condition seriously.

> *But the alternative was that if I didn't take it then I'm gonna end up*
> *back, back in hospital and what the consultant did do, when he was*
> *trying to explain what was the matter with me, he took me up to the*
> *top floor of the hospital where I say a load of sad cases and they*
> *were mainly old, em and they were wizened … So that was the*
> *biggest shock, and I thought, 'right!', I'm going to do as I'm told – I'm*
> *going to be a good boy, so I think that was a hard shock that he tried*
> *to give me, and as I say, at 22, it worked hardest.*   *(Brian)*

Brian explains how the shock tactic worked for him at this point. However, over time, Brian appears to have become resistant to the risk of long-term complications as his glycemic control is noted to be very unstable.

He does not see the need for education now, although it was noted through conversation and from his diary that his control is quite poor. When asked

about peer support around education, he does not see a need for this for himself but talks about how helpful peer support was when his daughter was diagnosed with diabetes. He seems to view education as helpful only in the early stages of diagnosis and in childhood.

As with previous cases, Brian has a clear lack of regard concerning high blood glucose readings, as illustrated by excerpts from his diary:

> *Before evening meal = 14.2 (8 units insulin), ok after 2 pints of beer (most enjoyable)*
>
> *Before bed = 13.5 (8 units insulin), no action; reading a bit high but ok, should be ok in the morning   (Brian diary extract)*

Brian's main concern is not to experience a hypo, as the acute episodes he has had have really frightened him, in his words, "it scared the shit out of me".

This therefore appears to be his main reason for self-monitoring his blood glucose, to give him peace of mind that he is not going to have a hypo, rather than informing any reasoned thinking around self-managing his condition.

> *It gives me a great feeling of comfort, I can go to bed and I can go to sleep happy ... that I'm not going to have a hypo during the night, and I'm going to wake up in the morning and there's no better feeling than waking up in the morning, you canna get a better start than that can you ... so that's why we do it.   (Brian)*
>
> *I want to see what I'm, what my condition is, during the day, and I get a lot, lots of good satisfaction, but I get a lot of relief about knowing where my blood sugar level is at a certain time during the day.   (Brian)*

When Brian shows his self-monitoring diary during the interview and the extremely high fluctuation in readings are noted, Brian comments: "… yeah, that's why I monitor so regularly". So, Brian is content that he is watching the levels, and does not worry or act on the instability of his glycemic control.

Although Brian refers to the fear of seeing patients with diabetes suffering from long-term complications and how this motivated him to take care of his diabetes at that point, he also understands that high and low blood glucose levels can put you at risk of such complications. However, there appears to be a

disconnect between this fear and his lifestyle choices and self-monitoring behaviours. It may be that time has softened the initial shock that he experienced at that time.

His support person has very little involvement in his self-management.

Brian recognises how self-monitoring can allow him control through allowing him to keep his blood glucose levels higher than recommended, which allows him then to partake in lifestyle activities (going to the pub most afternoons), without fear of a hypoglycemic episode.

Brian is not self-conscious about testing, but, in the same way as the previous patient, he would not consider taking his testing equipment when out socially, or testing at these times. He is of the opinion that this is his time and he does not want any barriers to enjoying this time.

External structures

External structures in this case relate to how Brian engaged with health services and his peers. Brian attends reviews regularly but admits to not taking on board much of the advice given. He seems to see reviews as things that need to be done to show he is caring for his diabetes but not something that too much attention needs to be paid to. So he does not link advice and direction with better outcomes.

Brian views the diabetic clinic and the diabetes nurse as the only HCPs to discuss his diabetes with, and would not consider discussing his diabetes and self-management with his GP outwith these visits.

> *Just like I wouldn't think of asking my own GP and speaking to him about diabetes. I appreciate they may have some knowledge about diabetes, but they won't have any specialist knowledge ... in fact I would probably be better informed on diabetes than they would be, you know, so I wouldn't want to waste their time.* (Brian)

When asked about goals or targets Brian becomes quite passionate that he is the one who should be in charge of his diabetes control, and gives the

impression that he does not want to be dictated to or controlled by anyone telling him what levels he should be achieving.

> *I appreciate that anybody can sit with bits of paper in front of them with targets of; if you reduce this by so much or if you increased that does, or if you have an extra injection, but it's me that's gotta live with it you know, it's not the doctor, it's not the dietician nurse, it's not the local GP, you know it's me that's gotta live with it, right and my intentions to live with it as best I can, but without it dictating to me what I should be doing ... em, I want to live a reasonably normal life ...*   *(Brian)*

Brian's feelings about this aspect have clearly been noted by his identified HCP who comments that this man is stuck in his ways and is going to do his own thing regardless.

Brian's partner has gained her understanding from living with her partner and, as mentioned previously, her interpretation of target levels is particularly high, suggesting that Brian's own goal is to main higher than normal levels.

<u>Actions</u>

Actions in Brian's case were generally related to how he uses his knowledge, experience and beliefs to self-monitor and manage his diabetes. These actions are generally responding to testing whether blood glucose levels have dropped and ensuring levels stay at the higher than recommended level to avoid problems in the short term. There is no long-term thinking or problem solving with regard to preventing blood glucose levels being outwith the recommended range.

Brian tests regularly throughout the day when at home to allow him to take immediate action if blood glucose level drops lower than the level he is comfortable with.

He clearly identifies that his most unstable glycemic periods are related to when he has his daily visit to the pub.

> *But you'll notice that the higher or the highest ones are all about the tea time mark … because, most days I go out and I have a couple of pints of beer, about 4 o'clock.*   *(Brian)*

Brian is very open about lifestyle behaviours that affect his diabetes and is clear that his is willing to accept the consequences of going to the pub in the afternoon daily for alcohol and a cigarette. He dismisses advice in relation to this.

> *(laugh) No, I'm laughing now because ... my conversation with the eh consultant tends to go the same way all the time … like he says stop smoking, but I still have the odd cigarette.*   *(Brian)*

Although he talks about keeping lifestyle measures in check (smoking and alcohol), his partner has a different interpretation of this.

> *He smokes far too much and that's one of the things you cannae do, well you're not supposed to do eh ... em, I don't know how, well I don't know, it would be, it's just ridiculous the amount of cigarettes he smokes, but he knows that himself.*   *(Brian's partner)*

He displays a strong need not to be different from his peers and not to be controlled by his diabetes or those who oversee it.

> *I'm going to try to live as normal a life as possible.*   *(Brian)*

It is noted through conversation with Brian, as well as Brian going through his self-monitoring diary during interview and from diary extracts, that his control is poor with significant fluctuations in blood glucose levels from the lower side of normal, to above normal levels. During the interview, when the interviewer comments on these fluctuations, he agrees and comments that this is why he tests, therefore suggesting that by testing, he is actually doing something about the poor control.

Doctor Whitby also comments on his diary extracts, stating that he has a view of normal for him rather than what is recommended. This appears to be for awareness of fluctuating levels, rather than to problem solve and determine how best to avoid them.

> *He will have a view of normal for him rather than the gold standard we would suggest.* *(Dr Whitby comments on Brian's diary extracts)*

Brian's big motivation to test is that he feels that by testing he is looking after his diabetes.

> *Right, I'm 65, I'm going to start looking after meself, so if it takes a few extra minutes a day to do the blood glucose monitoring then I haven't got a problem with it.*　　　　　　　　　　　　*(Brian)*

However, he only takes actions in the short term, mainly in avoidance of blood glucose dropping and reducing his risk of a hypoglycemic episode.

Outcomes

Outcomes for this case relate to the results of Brian's behaviours around testing and management. Although Brian experiences poor control and maintains blood glucose levels higher than recommended, this is not fully reflected in his HbA1c levels. This was noted by Podiatrist Colin who stated that these levels have remained stable.

> *His HbA1c wasn't bad, in fact it was almost exemplary compared to some of them we get.*　　　　　　　　　　　*(Podiatrist Colin)*

This may also suggest that expectations are low in terms of what some HCPs expect patients to achieve, based on what they are observing from other patients in their care.

Brian still drives and refers to how SMBG allows him to continue doing this and he relates his quality of life to the ability to continue doing what his peers do in terms of lifestyle activities.

Key points from Case 5

Brian's main focus is on avoiding hypoglycemic episodes but not being restricted, and enjoying a social life with his peers which involves lifestyle behaviours which are not conducive to glycemic control. To do this, he uses self-monitoring to reassure himself regularly that he is not at risk of a hypo and keeps blood glucose levels above recommended limits; he thinks he is doing something useful by testing. He takes actions, does not problem solve and does not consider the prevention of glycemic instability.

Case 6

This case comprises the participant, who has been give the name Pauline. She is a 57-year-old retired nurse but who still works agency shifts in care homes. She was diagnosed with type 1 diabetes following cancer treatment. Pauline identified her daughter as her support person, but she did not return the consent to contact form. Pauline identified her clinic consultant as her HCP, who participated, and she returned her diary. This case therefore has two pieces of supporting evidence.

Internal structures

Internal structures for this case relate to Pauline's background as a nurse working in diabetes eye screening.

Pauline appears to consider that she has expert knowledge in diabetes because of her background. However, this is not demonstrated in her ability to self-manage her condition through problem solving. Her HCP also notes that she appears to understand on the surface, but she does not always act in a sensible way with the information she has and often needs help to interpret results and to decide what to do next. During the interview, she seems to want to give the 'right' answer because of her background and what she deems to be the expectation of her level of understanding. This may inhibit her ability to seek help or further information to support her diabetes self-management.

She refers to a course that she particularly enjoyed, which was very "hands-on", experimenting with food which appears to indicate that Pauline is a practical learner.

> Aye we got to your experiment with foods when working out the carbs … it was a great way to understand it, they used different plates you know made up so you could actually look at it.
>
> (Pauline)

Perhaps it is the theoretical presentation of self-monitoring and self-management which may be more difficult for her to understand. She also mentions finding the peer support helpful during this course.

Pauline is concerned about blood glucose levels going too high as well as too low and explains that she has checked for ketones before when levels have gone too high.

Pauline has a good understanding about the risks associated with poor diabetes control but there is a disconnect with the problem solving processes in her self-management, as noted by her consultant, and how she explains that she can use self-monitoring to allow her to eat things she likes.

External structures

External structures were related to Pauline's experiences when engaging with health services. She reported that when she was admitted to hospital, the general ward staff did not seem to have the necessary knowledge in diabetes management, as well as a lack of compassion, affecting her confidence in the care she was receiving.

> *I did have a fear … nurses on a general ward probably don't have a great diabetic knowledge … When I was actually admitted in the hospital, I felt the ward staff did not have much knowledge on diabetes and I felt I could see a lot lack of knowledge, I could pick up on, then, I just, I felt they weren't always sympathetic.   (Pauline)*

She provides an example of a situation when she was discharged from hospital and given the wrong diabetic regime due to a nurse misinterpreting what had been ordered. Pauline used her contacts within the hospital to clarify the mix-up.

> *I was lucky … I know the girls to phone … for me it wasn't that bad, but … for someone else with no knowledge whatsoever it would have been a bigger problem.   (Pauline)*

Pauline talks about setting targets at the beginning but not so much now. She seems to have a view that now she is over the initial diagnosis and associated education and analysis, she can just try to live normally without dwelling too much on her diabetes, rather than it being an ongoing analysis and adjustment.

Because Pauline has a background as a health professional, working in a diabetes-related field, she appears to feel her diagnosis is ironic and that she

should know all there is to know about managing her condition and laughs somewhat nervously when referring to this, perhaps suggesting that she would feel embarrassed if she was viewed as not being fully knowledgeable in diabetes management.

> *And the doctor said, 'What are you doing here? You can't have diabetes … I mean, to go for an operation and end up with diabetes, with all the courses I've done … and even although doing diabetes all the time because that's what I specialise in … eyes … and because I worked a lot with the diabetic nurses.* (Pauline)

There is a feeling here that Pauline is feeling judged about having diabetes and that she is justifying how surprised she was, as well as others, that she developed this condition. This highlights that some individuals feel that there may be a stigma associated with diabetes.

Actions

Actions for this case relate to how Pauline used her previous knowledge and skills to inform her testing and management. Pauline's main reason for testing is to allow her to drive and therefore work and provide control over her life. As noted with other participants, she sees self-monitoring as giving her the control to live normally.

> *I think being on the self-monitoring is as close as you can be to being normal, if you know what I mean … You know what your levels are you know em … I could eat this and that, if I wasn't coeliac I could eat cakes and things (laugh, laugh), do you know what I mean, so, but, so although I'm type 1, you do have that sort of advantage (laugh, laugh).* (Pauline)

She rates the importance of testing at 10 out of 10 because of the control it gives over her life.

In addition to Pauline's diabetes, she has also had to deal with cancer and, as mentioned previously, she benefited from peer support, noting the difference in what friends and those who have experienced a similar situation can offer.

> *I had breast cancer and much as your friends could sympathise and empathise, they still didn't know … I joined a group of ladies and all it was, was a chat and a coffee but it was people who knew how you*

> *felt, because they had actually experienced it … always better than someone that hasn't … like the diabetes course ... always better speaking to people that know because they have all got different ideas and that why I liked that course.* *(Pauline)*

Pauline talks about actions in terms of responding to abnormal readings before work and while at work, correcting insulin and taking glucose.

Pauline records her results in a diary and notes that there is a space to mark in unexpected results but she does not talk about doing this or trying to analyse or problem solve the results. Her HCP comments:

> *She neatly documents them all then doesn't always do an awful lot with them.* *(Dr Whitby)*

Pauline admits to not having good control, again, with mainly higher than desired blood glucose, particularly when away from home working shifts. This may be down to the driving requirement for working. She comments that she is working on this:

> *I'm a bit higher than it should be at times but again we're gonna work on this.* *(Pauline)*

As noted above, she takes short-term actions but does not seem to problem solve in the long term or in the prevention of her poor control.

When asked whether she would consider using new technology to assist with the management of her diabetes she views this as dwelling on her diabetes:

> *Ah yes, I'd have a try … I don't know if I would need it you know … em I mean I don't dwell on my diabetes, in that I would be looking at it every day, you know ... I mean I wouldna do that.* *(Pauline)*

She views her confidence level as being high, 8–9 out of 10, the reason being that in her view, diabetes is something that will never be fully understood:

> *It's constantly changing, diabetes, and nobody will ever completely get their head round it, all you can do is your best to manage it.* *(Pauline)*

Pauline gives the impression of testing but looking at the results individually rather than together. She gives an example of experiencing poor control and then going to the diabetic nurse with her diary, who identified late shifts as the problem, and admitting that she had not seen this in the results. She talks about this being complex and is of the view that only those overseeing diabetes could do this: "Patterns; ah, They, the doctors, could look at that and see" (Pauline).

Outcomes

Outcomes for this case relate to the results of how Pauline used her previous knowledge and skills to manage her condition. Pauline manages to maintain a level of control which allows her to continue driving, making work easily accessible for her. This is her key priority and she is therefore afforded independence, assisting her to achieve a level of quality of life. However, the outcomes in terms of stable glycemic control to reduce the risk of diabetes-related complications are not being achieved.

Key points from Case 6

Pauline has background knowledge in diabetes because of previous employment in this area but this does not fully assist her with understanding her own self-management. As noted with Angus, this participant is well educated and also an HCP but is not managing her condition. Interestingly, it appears that because she has this knowledge and healthcare background, she feels she should be an expert, which may affect her ability to seek help. Her self-monitoring and associated management is limited to taking actions in the short term rather than problem solving and analysis.

Case 7

This case comprises the participant, who has been named Alison. She is a 49-year-old married woman with a grown-up family. She was diagnosed with type 1 diabetes at the age of 6 years. Alison is an Occupational Therapist and therefore has a good understanding of the health care system. She identified her friend and work colleague as her support person, who consented to participate, and her identified HCP is her diabetes specialist dietician (an

extended scope diabetes specialist), who also consented and participated; she has been named 'Dietician Sally'. Alison returned her patient diary and therefore has all supporting evidence.

<u>Internal structures</u>

Internal structures in this case relate to Alison's knowledge and skills and her professional background. Alison talks about education in a positive light, referring to when her parents attended education when she was diagnosed. She also talks about the benefits of peer support in education, referring to a course she attended recently where she happened to meet a neighbour who she hadn't realised had diabetes. It appears comforting to Alison to know that there are others in her community living with the same issues as her. She talks about the benefits of finding out what others do, which she had previously felt she did not need.

> *That was quite useful you know in a way… and in fact it was interesting to hear from other people and what they do in given circumstances … I suppose it's kind of peer support ... I mean I've never felt I need peer support from anyone else with type 1 diabetes, I've just gone and done it myself … I think that's more to do with my confidence in feeling that … it's my body … it's my condition and therefore I don't need any support from anybody else kind of thing.*
> *(Alison)*

Alison's support person is informed about chronic conditions due to her working background in health. She feels the key to self-management is being well informed but feels that education only kicks in when a new type of management or change in management occurs.

Alison has a good understanding that by keeping her blood glucose levels stable, this will significantly reduce her risk of diabetes-associated complications and this is her long-term goal.

> *Well, obviously it's for ... the kinds of, the thinking about long term, what could actually happen if my blood sugars weren't within, you know, the agreed em levels ... you have to think about the eyes, your kidneys and your peripheral circulation … you know that kind of thing … that's the long-term goals.* *(Alison)*

Both Alison and her support person also refer to the effects of self-management on quality of life in relation to condition-associated risks. This higher level understanding of implications relating to how one self-manages in terms of developing complications and how this can affect quality of life, may be a factor that motivates Alison in her approach to self-monitoring and associated management.

Although Alison identified her friend as her support person, this was due to her husband not being available. As well as her friend being a support in terms of discussing and considering her diabetes, Alison also discusses how her husband is actively involved in her diabetes, they discuss her management regularly, and he reminds her prior to meals when it is time to self-monitor.

Alison's friend also notes that she has a good support network who all take her diabetes into account when organising social activities. Examples of this are: she is accompanied at work on home visits by another colleague, and social events often involve alternatives to alcohol.

Alison talks about the forward thinking and preparation she does to facilitate her self-monitoring, for example, always having equipment with her, taking a big enough bag for equipment, and factoring in time.

Although Alison identifies a couple of barriers to testing, she then goes on to talk about how she overcomes these barriers, for example, using different fingers for the finger prick test, and allowing additional time after testing to take actions.

Alison's friend notes how open she is about testing and injecting in public:

> *She's never shown any particular embarrassment about it … it's just part of who she is and the folk who know her accept this … anyone who's ignorant enough to stare, just stares, she doesn't bother.*
> *(Alison's friend)*

External structures

External structures for this case relate to Alison's positive relationship with health services, support people and peers. Although Alison's control is not

always as stable as it should be, she can see that HCPs understand that she is doing her best and she is grateful for their praise for her efforts, which she feels is motivating for her.

> *… they will say … you are doing really well, you are doing what you can do with the tools you have.* (Alison)

However, she has encountered a lack of understanding from HCPs who are not involved directly in diabetes care. She gives an example of when she had her daughter by caesarean section and was handed the baby to feed soon after delivery and then was just left on her own. Her tea was at the end of the bed out of reach and she began to go into a hypoglycemic episode. Her husband fortunately arrived and was extremely angry when he realised the lack of consideration for her diabetes or the ability to deal with it.

> *My husband is saying, 'You got glucagon?' and them saying, 'We don't have glucagon on the ward … em … you'll have to wait until we get the doctor to put in a glucose drip to give her glucose,' and him saying, 'What the!! Don't be stupid, have you got Lucozade have you got this have you got that' … what a palaver it was … and it was pretty scary … that they had nothing in the ward to deal with this … you know.* (Alison)

She felt that it was not within the midwives' remit to look after a mother with diabetes, only a mother with a baby.

In addition, Alison has experienced health services' lack of understanding around the urgency for insulin, and recounts a situation when an insulin cartridge broke when she was loading it and she urgently required a replacement.

> *So I phoned up NHS24 … the nurse phoned back and you have to give the whole spiel again, she said, 'Well wait till the morning,' I say: 'Can't wait, well actually No! I need this,' she says … 'Right ... ok, well you'll need to come to Stirling Royal Infirmary,' so I'm ... 'Right … I know,' and in fact actually I had to take my two kids with me because my husband at that time was on the roads so he was on night shift or back shift. Right so you come to there … they then can't do anything because they've not got access to another, another gadget ... they say … um, we'll need to get an on-call pharmacist to come in to go to the diabetic unit to get another one, so you'll need to go away home again and come back at 8 o'clock at night and ... what*

> *a palaver ... so it was the, the complete lack of kind of understanding and it might, you know and it was a kinda of, an indication, I mean I fed it back to the diabetes, you know the next time I was at the diabetic clinic because I thought well if anyone else had that, what is the way of actually getting another … but, you know they obviously they didn't really appreciate the urgency (laugh) of it.   (Alison)*

Alison also refers to how she does not like to be patronised by HCPs, particularly GPs who do not know her and states: "You know, some treat me as if I don't know what I'm actually doing" (Alison).

<u>Actions</u>

Actions for this case relate to how Alison's knowledge, understanding and positive relationships are reflected in her testing and associated management. Alison tests regularly and uses her results to problem solve in the immediate and the long term.

> *… you know ... I'm using the tools that I've got to best judge what I'm going to do.   (Alison)*

There is a strong sense of Alison viewing her diabetes as part of her, as opposed to a disease or condition.

She is very aware that diabetes does have control over her life but she explains how hard she has to work with this and how sometimes this can be frustrating and exhausting.

> *… because you think doing the best you can, you're doing as much as you can but something else is controlling what's going on, and it can feel … very tiring.   (Alison)*

She makes the point of how important it is for people to be responsible for their own health. She ensures attention to testing and self-management, regardless of small obstacles. For example, similar to other participants, she often is without the self-monitoring diary supplied at times by health services but she overcomes this by accessing her own diary.

> *I've got a em like a small book and in fact the one that I'm using I have been using since 2009, so it's not one of these ones I've been given at the diabetic clinic, because sometimes they don't have*

> *them, it's like a red and black you know one of these booklets you get at WH Smith's, em with lines on it and I draw lines so they've got wee squares and I put the date, the, the amount of insulin I'm taking, the the time of my bm and put my bm in, so and then sometimes there are wee comments written at the side about, I've done exercise, I've done whatever.*   *(Alison)*

She also facilitates having her equipment with her at all times, noting: "It's always with me, wherever I go the device comes with me" (Alison).

Both Alison and her support person as well as her patient diary give a detailed account of the many different actions she takes following testing and the many considerations she takes into account, with noted future planning and analysis of results.

Alison demonstrates a positive approach to lifestyle behaviours, paying significant attention to health, diet and physical activity, which form a large part of her social life.

Diary extracts demonstrate how she relates her self-monitoring and self-management to lifestyle:

> *4.2 Normally do this prior to breakfast and going to a Zumba class*

> *After exercise = 10.1 Need to check the effect of exercise on my Blood sugar*

> *At tea time I took less insulin as going to Zumba and exercise reduces blood sugar.*

> *Tested ½ way through Zumba class (7.30pm) as exercising my blood sugar can reduce = 2.8!! took 4 X glucose tablets to raise blood sugar*

> *Tested at tea time = 11.7, did not do anything as going to Bodyjam and this will reduce blood sugar, no tools used*

>   *(Alison's diary extracts)*

Alison refers to problem solving in relation to her results throughout the interview and in her diary extract. Her support person and HCP also note how she problem-solves, looks for patterns and makes changes to her management

in relation to this. Although Alison rates self-monitoring of high importance (10 out of 10), she rates her confidence low (7 out of 10). This is down to the unpredictable nature of her control at times and the need to sometimes use some guesswork.

Alison has a positive approach to reviews and, as well as sharing her results with clinic staff during reviews, she also talks about discussing her results with her husband and her friend. She does note that she would not consider sharing her results with her GP.

Outcomes

Although Alison does not always achieve the stability of control she would like, her level of engagement and forward planning in terms of management appears to allow her to balance a busy life that incorporates work and many social and physical activities. Her ability to continue driving makes work and social activities easily accessible to her.

Alison's main reason for testing is to keep her HbA1c at a good level and so reduce her risk of diabetes-related complications. Although Alison has recently experienced glycemic instability, her HbA1c has remained stable. Unlike other participants, Alison understands the importance of maintaining control through self-monitoring, even when HbA1c is normal.

> *… so that it's been very erratic over the past few weeks … actually to, to my overall control, it's not made any difference interestingly enough, you know the HbA1c …*   *(Alison)*

Summary of Case 7

Alison pays great attention to monitoring and associated self-management, considering energy requirements for the rest of the day and analysing results in combination with each other and external factors. Alison has a good support network through her friends and family, with her diabetes being a very open and talked about topic. This appears to allow her to very much engage with her condition, viewing it as something that is part of her which constantly needs

work and consideration in achieving the ultimate goal of reducing the risk of diabetes-related complications.

Case 8

Case 8 comprises the participant, who has been named Bill, a 71-year-old retired non-professional man who was diagnosed with type 2 diabetes at the age of 45 years. He was initially treated with diet, then oral medication, but after a year was then put on to insulin therapy. He is divorced with a grown-up family and lives with his partner. His identified support person is his partner who agreed to participate, and he identified his podiatrist as his HCP, who did not return the consent to participate. Bill did not return his patient diary and therefore has one piece of supporting evidence.

Internal structures

Internal structure for this case refer to Bill's knowledge and skills around testing and managing diabetes which have been more recently acquired. Bill and his partner consider themselves to have a good understanding of diabetes which has been gained through experience but have not been offered any formal education.

His partner notes a need for re-education after a certain length of time and for her the need for education around dealing with emergency situations.

> *I do feel … possibly years down the line, there needs to be a kind of re-education … he's had it for over 20 years … and for people like me, just things like, if he did collapse or lapse into a coma, to know I would know what to do and not panic.*   *(Bill's partner)*

Bill understands the link between working to control his diabetes and the reduction in diabetes-related complications, describing this as: "So it's just general good health, trying to keep it as level as I can" (Bill). He also links the need to control lifestyle factors such as diet, smoking, alcohol and physical activity in reducing risks.

He has experienced other chronic and serious conditions, having had a stroke previously and having being diagnosed with coronary heart disease. He

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acknowledges the effect of having many conditions and refers to having seen the size of his medical notes when he attends reviews.

> *You always know it's your file when you see it sitting in the counter cos it's it's that thick (laugh)!*   *(Bill)*

As in the previous case, Bill notes a barrier but then explains how he has overcome this, for example, self-monitoring has affected Bill's ability to play the banjo, so he now does not test with the important fingers for his instrument playing.

Like many of the other cases, Bill is most aware through physical symptoms when his blood glucose level drops lower than it should be, but, in contrast with the other cases, he works equally as hard to keep his level from going too high as he does to prevent them from dropping too low.

External structures

External structures in this case relate to experiences with health services. As noted in previous cases, Bill's partner feels that health services, other than diabetes services, do not consider diabetes enough. She gives the example of when her partner was admitted for operative procedures requiring an overnight fasting. Bill has been told on more than one occasion that he will be taken early because of his diabetes but in practice this then does not happen.

> *… you're a diabetic, we'll take you first thing; and then its sometimes late morning before he's taken … I'm not diabetic and I would find it very difficult to last that long without any food or drink whatsoever … and it's more difficult for him … so I think there needs to be a better understanding … it does concern me when he's had to go for hours without food or drink.*   *(Bill's partner)*

As in the previous case, Bill also refers to occasionally feeling patronised by HCPs:

> *… things like, come on Mr … just a little prick; I didna like that treatment at all.*   *(Bill)*

Actions

Actions for this case relate to how knowledge and skills were used in his testing and management. Bill takes actions in relation to blood glucose results that relate to the immediate situation, but also takes actions in relation to longer-term thinking over the day.

> *You know if you're going to be working hard, you know when I was taking a fireplace out, it went down low as anything, because I was using up the energy, so I work it out, so today em like cutting the grass, I could go, after that it would probably be low because I've used it all up, eh and you know the next day if you're then sore, you know it's high, plus, plus you watch what you're eating.   (Bill)*

Bill describes the emotion of having to tell his family he had diabetes. The chronic nature of the condition seems to evoke emotion.

> *I came home and of course I've got a wife and three kids … I had to tell them that I had it … it was very difficult … I can't explain … (Bill)*

His partner also refers to emotion in relation to the frustration that Bill feels when he has worked really hard to control his diabetes and then gets a blood glucose result that he has not expected and that does not reflect how careful he has been.

> *It can be frustrating, you know, you want to show that having had a good couple of days its reflected in your readings and you feel good, but it is very frustrating when you have had a couple of days, but it's not reflected, you think, ok, why am I doing this, you know; is it making any difference.   (Bill's partner)*

Bill does undertake a level of problem solving, considering carbohydrate intake and physical activity expenditure over the rest of the day with the aim of preventing instability in his blood glucose level.

Bill documents his SMBG results on a spreadsheet and keeps all results and review documentation in a file. He does look at the results together over a period of time, but at too limited a level, as he has difficulty understanding why they are sometimes unexpectedly outwith normal control. Bill's partner also comments on how he and his HCPs attempt to look at patterns:

Although he writes these numbers down, there is no logic to them … and sometimes they just can't work it out, they don't see a pattern, you know sometimes there is no rhyme nor reason to it.

(Bill's partner)

Bill demonstrates compliance through explaining how he has had to make many lifestyle behaviour changes over the years, not only with his diabetes but also with other conditions he has had. He views that the experience he has had making lifestyle changes for other conditions has made it easier when making changes in relation to his diabetes:

You just get used to it … Wee things, like if you're going out for a drink, stop and have a glass of water for a couple of rounds, things like that, that's just the kind of advice I've built up.   (Bill)

He takes seriously his health and conforms to management regimes and also notes his surprise that others would not do the same. He talks about how he was asked whether he was taking his medication and was completely shocked.

There must be some people not taking their tablets! You know, for him to ask me that.   (Bill)

Bill rates the importance of self-monitoring and his confidence in undertaking it as10 out of 10. So, although he experiences unstable levels in his glycemic control, which he cannot explain, he is confident that he is doing all he can to self-manage his condition.

As in case 4, Bill is reviewed alternately by his GP and the hospital clinic and also notes the problem of both reviews occurring at the same time and then having long periods when he is not reviewed.

Outcomes

Outcomes for this case include health outcomes in general as well as the results of how Bill manages his diabetes. Bill has experienced many poor health outcomes; in addition to being diagnosed with diabetes he has also been diagnosed with cardiovascular disease as well as cancer. The effect of previous poor health outcomes appears to have motivated Bill to take

responsibility for his condition and make the necessary changes to allow optimal self-management.

Bill's control is stable enough to allow him to drive, affording him independence, and so maintaining his quality of life.

Summary of Case 8

Bill self-monitors regularly and tries to conform to self-management through lifestyle and some level of analytical thinking and problem solving. The importance of working hard to maintain good glycemic control and to prevent complications appears to be influenced by having experienced other serious conditions in the past.

Case 9

Case 9 comprises the patient, who has been named Peter, a 61-year-old retired policeman, who was diagnosed with type 2 diabetes 18 years ago. As in the previous case, Peter was initially treated with diet and oral medication and then moved onto insulin therapy. Peter is divorced and lives alone. He was unable to identify a support person, stating that he only sees ex-work colleagues and never discusses his diabetes with these friends. He identified his practice nurse as his HCP, who did not return the consent to contact. Peter did return his patient diary and therefore has one piece of supporting evidence.

Internal structures

Internal structures for this case relate to his acquired knowledge and skills. Peter has gained his understanding from consultations following his diagnosis and experience of living with the condition. Peter has not been offered any formal education. He notes that he was required to educate his work colleagues when still working as a policeman, on what to do should he become ill while on shift.

Peter's key concern is blood glucose levels dropping, especially in the evening, as he lives alone. This concern appears to push Peter to keep his levels on the higher side of normal.

> *My thought process is not to allow it to go down … so sometimes going to the mid-teens when I check it.*   *(Peter)*

Peter's reason for testing is focused on preventing blood glucose levels dropping low and maintaining his ability to drive. This is noted in his diary extracts as well as throughout the interview.

> *To make sure level high enough to ensure no hypo during the night 10.9 = no action*
>
> *11pm before bed to ensure no hypo during the night – 7.2 = took 2 digestive biscuits to boost sugar level and prevent hypo during the night*   *(Peter diary extracts)*

Peter notes his reason for documenting results from testing is to provide his results to HCPs during review:

> *I note my results in a diary for reference if required during consultation with the practice nurse.*   *(Peter)*

Peter does understand the long-term risks associated with diabetes, which he applies to complying with management and his lifestyle.

> *There's no doubt that it changes the way you live your life, it makes you more aware of your lifestyle, how you live your life eh, and the fact that it can have serious consequences on your life span.*
>   *(Peter)*

Peter's main barrier to testing is if he is doing something socially. He refers to situations when he has been going out and forgot to test before he went out, and then experienced a hypo and unstable blood glucose for some time after.

> *It can be ... maybe annoying or a bother but it's is as I say, if I'm doing something out of the ordinary, that could make it a wee bitty kind of awkward as well.*   *(Peter)*

He does not consider taking his testing equipment with him when he goes out.

> *I mean the actual practicalities of doing it, because one of my old mates, he takes his machine wherever he goes to type of thing, but I would find that a wee bitty awkward, you know more, if I'm at the football or something like that.*   *(Peter)*

He describes testing as: "a bit of a bind at times" (Peter).

When asked, Peter understands the risks associated with diabetes, but he does not mention risks when asked about reasons for testing.

The fact that Peter was unable to identify a support person, and that he states that he only socialises with ex-work colleagues, with whom he would not consider discussing his diabetes, highlights his isolation in terms of diabetes-related support. This does appear to influence how he manages his diabetes as he regularly refers to the fact that he lives alone when discussing this.

External structures

External structures relate to how Peter linked with health services and his lack of support people to assist him or to discuss his diabetes management with. Peter's diabetes is managed jointly with his GP practice (his practice nurse) and the hospital clinic. He also mentions that he would not consider discussing his diabetes or blood glucose levels with his GP.

Actions

Actions for this case relate to how Peter used his acquired knowledge and skills to manage his diabetes. Peter self-monitors regularly in relation to driving, meal times and physical symptoms:

> *Right, basically, if I know I'm going to be going out driving, I give it a check eh because I know that's very important, eh other than that, normally about twice a day, it's as I say; morning, afternoon, evening, that's the three ways I split it up … or feeling a hypos … aye ... basically it is very much a routine thing, and also if I've eaten something unusual.* (Peter)

Peter takes actions in the short term rather than problem solving with longer-term thinking and planning. This was evident when Peter refers to incidents when he has gone out socially and then experienced unstable control.

When looking at results, Peter appears to see them individually rather than looking at results over a period of days to identify patterns. He talks about isolated situations where his control has been unstable and although he

considers factors which may have had an impact on his control, he does not appear to fully join incidents together to look at a pattern.

Peter's reviews are shared between General Practice and the hospital clinic. He views the hospital staff as experts in his condition and states that he would not consider sharing his results with his GP.

Peter rates importance and confidence at 8–9. This is due to spells when he has been busy and then experienced unstable blood glucose levels.

Outcomes

Outcomes for this case relate to the results of how Peter managed his condition. Similar to several other participants, Peter's quality of life is dependent on his ability to drive and therefore his main outcome measure was successfully keeping his blood glucose at a level which allows him to do this.

Summary of Case 9

Peter focuses on keeping his blood glucose levels high to avoid hypoglycemic episodes. He takes immediate actions based on self-monitoring results but demonstrates little longer-term thinking and planning to allow problem solving or analysis to occur. He does understand risks associated with diabetes in terms of diabetes-related complications and is careful to conform to lifestyle and medication. However, he does not link this to his glycemic levels being unstable or too high at times.

Case 10

This case comprises the participant, who has been named Charles, a 65-year-old male university lecturer, who was diagnosed with type 2 diabetes in 2002 at the age of 57, and is treated with insulin. Charles lives alone and is about to retire. Similar to some previous cases, Charles was unable to identify a support person. He identified his practice nurse as his HCP, who did not return the consent to contact form, and Charles also did not return his patient diary and therefore does not have any forms of supporting evidence.

<u>Internal structures</u>

Internal factors for this case relate to Charles' high educational level and ability to take on information and processes, yet there appears to be a lack of awareness in relation to how self-monitoring should be undertaken and its importance. Charles' understanding of self-monitoring has been generated in the last few years when a student introduced him to the process and provided him with equipment.

> *I was introduced to self-monitoring by accident by a student we had on the programme, and I'd said I had diabetes and she actually got me the equipment erm and basically explained why people do it and why some people don't do it and all that ... um ... it's like about 12 years ago or a bit less, I don't recall ever having that conversation at that stage with a health professional.*   *(Charles)*

Since then, his knowledge, understanding and expertise in self-monitoring has been sporadic.

> *Well, em, I, I suppose so, I mean kinda like em, experimenting, trial and error kinda thing.*   *(Charles)*

He has never undertaken any formal education:

> *I mean I've never done anything like a proper formal course like DAFNE or anything, but kind of got the idea of being able to estimate what ... er what the effects of a certain kind of meal was likely to be.*   *(Charles)*

However, he explains how he has observed the effects of food and insulin on his blood glucose:

> *… glucose levels shoot up over a two-hour period, or something like that and then starts to kind of come down again, erm, so I kind of worked that out … kind of got the idea of being able to estimate that … erm and what the effects of a certain kind of meal was likely to be.*   *(Charles)*

He has never been offered any formal education in self-monitoring or self-management. He does, however, mention his involvement in a clinical trial, where he tested and documented his self-monitoring results over a period of

time. He describes this experience as a missed opportunity to provide him with education and assessment of his condition.

He has been made aware of educational courses by the student who introduced him to self-monitoring and he states that he would consider attending an educational course but would need to be convinced that his time investment would be worth it.

Charles talks about how he has learned to demonstrate his understanding of diabetes to HCPs, in that if you emphasise that he views it as a severe and life-threatening condition, then they "kind of relax".

> *I've kind of learned that's the patter, if you say, 'Yes I've got a life-threatening disease that will kill me if I'm not careful,' or words to that effect, they kind of relax, er at that point, because they obviously realise that they don't have to go into this and that, if I call it propaganda.* (Charles)

He describes this approach as "propaganda", and implies that he is manipulating the situation to keep them off his back.

Charles frequently refers to his blood glucose levels "shooting up" and he quotes glycemic levels that are significantly higher than the desired upper limits, and describes levels as being regularly in the "teens".

As in the previous case, Charles is concerned about levels dropping at night time, especially as he lives alone and describes this as "risky". It appears that he does not associate risk with levels being in the teens but focuses instead on the acute risk of having a hypoglycemic episode during the night.

Again, Charles understands the risks associated with unstable blood glucose levels but this does not always come to his mind when experiencing higher than normal blood glucose levels.

Charles makes several references to having a sweet tooth and this being a barrier for him managing his diabetes:

> *I have a sweet tooth ... and that was part of the problem adjusting to this ... and it doesn't just go.* (Charles)

However, he then goes on to explain that he uses self-monitoring as a tool to overcome this barrier, so allowing him to see how high his blood glucose has risen and providing him with control to eat what he wants at times.

Charles is also asthmatic and compares diabetes with asthma:

> *I have asthma as well but if you don't medicate with asthma, you can pretty quickly feel the effects, diabetes, at least at that stage is really a lot more insidious.* (Charles)

He considers diabetes to be more insidious in nature than asthma, where it is much more obvious if he does not take his medication, and he quickly feels the effects. This insidious nature, particularly of high blood glucose levels appears to be why many do not make the connection with the increased risk of diabetes-related complications.

External structures

External structures for this case relate to Charles' perceptions of health services and how this influences how he interacts with and manipulates these services. Charles talks about experiences with health services where he felt that the staff did not fully communicate with him about his diabetes. He gives the example of when he was admitted due to a fractured ankle which required surgery. While awaiting surgery he got the impression that they were delaying taking him until his glycemic level was more stable and he was left for a long period of time fasting.

> *… erm and my impression was that they were kind of hesitating and waiting because my sugar level was quite high, I mean I hadn't eaten anything so I don't know … I got the impression they were actually deferring the surgery but it wasn't communicated … a lot of the information you get is actually quite vague when you are in hospital … you should make a point of saying, 'I want to know!' (bang, bang on the table)* (Charles)

Charles states that he has never been given a goal to aim to achieve in terms of blood glucose self-monitoring. In his opinion this is because HbA1c is the important level he should be looking at.

When Charles explains that he has never been guided by an HCP in relation to self-monitoring, he points out that it has never been raised as being important; otherwise he would pay more attention to self-monitoring.

> *I don't know, that's it … it's never raised, it's never been I mean right from the off, I mean it wasn't discussed ... it's never really been presented as a significant thing, I don't think, I mean if anybody had at any stage shown an interest in my record on the device or if they'd ever said, 'Maybe you should be documenting this on a regular basis,' you get a signal then about its significance which I don't really think I've had, so it never, I don't ever recall it coming up as an issue, it's just basically, 'Ok, we'll do the usual round of blood tests and so on we'll screen those and if there are any problems then we'll call you back in.'* (Charles)

Actions

Actions for this case are an example of limited information/education provision, resulting in a lack of awareness and low levels of self-management. This may be due to Charles giving the impression of being a fully informed expert. Charles takes actions in the short term in relation to his self-monitoring results. He does not appear to plan further than a couple of hours in advance when he predicts his levels will have adjusted to a certain level.

He has never recorded his results other than when he was involved in a clinical trial.

Although there is no regularity to Charles' self-monitoring, he notes that there are times when he is more in the habit of testing than other times. He notes that he is less likely to be in the habit of testing when he is outwith his normal routine, for example, at the time of interview he was in the process of moving home and therefore outwith his normal routine.

Charles admits that his reason for testing is often to check his levels after eating something sweet or not what he would normally eat, as well as in response to physical symptoms of abnormal blood glucose. For example, he will often test if he is on the train due to the limited food availability, thus requiring him to eat foods which may affect his control.

Here he is clearly referring to not acting on high blood glucose levels, as he does refer to reacting to the physical signs of low blood glucose levels.

He rates the importance of self-monitoring as low, at 7–8 out of 10. This may be due to his viewing HbA1c as being more important.

As Charles tests and takes actions in the short term, generally related to him observing that levels do not go too high after eating something high in sugar, there is little problem solving in the longer term noted, and no forward planning or analysis of blood glucose results together.

Similar to importance, Charles rates his confidence in self-monitoring and applying results low, at 7–8 out of 10. He reports that this is due to never having discussed his self-monitoring and associated self-management practices with any HCP other than the practice nurse. He gives the impression that he is in the dark in relation to self-monitoring. His GP is only concerned with his HbA1c and he is reassured that his HbA1c is normal and this is the more important variable as far as he is concerned.

> *I suppose that I'm not going for the full whack because I have never discussed this with a health professional … erm … but … I suppose there's a lot of emphasis placed on that one variable, but … as long as I'm reaching the right level on the HbA1c, I think I must be doing something vaguely ok.* *(Charles)*

There does not appear to be any regularity or routine to his self-monitoring.

When asked about patterns, Charles refers to having an understanding of his own patterns of how levels will rise and fall in relation to his carbohydrate intake.

> *So … obviously on a daily basis glucose and sugar levels go up and down depending on how recently you've eaten and so on … and you kinda learn … I've learned what that pattern looks like.* *(Charles)*

He therefore considers that this knowledge is enough and that he does not need to look at his actual self-monitoring results together.

<u>Outcomes</u>

Outcomes for this case relate to Charles' lack of awareness of the importance of day-to-day fluctuations in blood glucose. Charles views HbA1c as the key indicator of outcomes; he reports that this indicator for him remains fairly stable and therefore he feels content that he is doing what is necessary to achieve good health outcomes.

<u>Summary of Case 10</u>

Charles has never been fully educated in self-monitoring and its application to self-management. Consequently, he self-monitors in an ad hoc manner, generally to avoid hypoglycemia and to monitor how much above normal blood glucose levels have reached.

He does understand the risks associated with poor glycemic control, but this understanding is not applied to his problem solving or analytical thinking around his self-management.

6.3 Additional supporting data

Pilot telephone interviews were also undertaken with two relatives of individuals with diabetes.

1. Mum of an young adult individual with diabetes named Carol
2. Daughter of a father-in-law with diabetes named Sarah

Some interesting and very rich data were obtained during both interviews. It was felt that the richness of this data informed the interpretation of other support persons' interviews and has therefore been integrated into the second-level and final analysis which forms the following section.

The HCP views were all analysed regarding self-monitoring in general, as well as their views of self-monitoring in relation to the individual who had identified them.

In addition, the opinion of a Diabetes Consultant was obtained. This provided clinical interpretation and discussion of the diary extracts. Again, this was

deemed to contain important information which has been integrated with the second-level and final analysis in the following section.

6.4 Second-level analysis – identification of key threads

Following the within-case analysis, the initial themes, along with the case analyses, were further analysed and secondary coded to form key threads, again using NVivo software, to form the first-level cross-case comparison. These 12 key threads, along with their sub-level themes, are described below in Table 5 below.

Table 5: Key threads and sub-level themes

KEY THREAD	SUB-LEVEL THEMES
Disengagement: don't want to be different	• Forgetting to monitor or take insulin • Individuals not wanting to draw attention when monitoring • A need to feel the same as social peers through doing the same things and making the same lifestyle choices as their social peers • The importance of normality and 'rebellion' allowing them to maintain this normality • Having the right balance • Not wanting to look at results too closely • Not engaging – so that they do not have to think about their diabetes too deeply, therefore absolving them of responsibility • Not wanting to be judged (especially in relation to the link with diabetes and obesity)
Control – a desire not to be controlled by others or their condition – a need to feel in control and not feel surveillance	• When questioned about their management by support people and HCPs this causes resistance • Poor collaboration and engagement with HCPs: feelings of surveillance • Feeling that SMBG affords control • Rebellion: not adhering to management to varying levels • The monotony of doing the same thing for a condition which will never be cured, inducing feelings of resentment • Expressing the need to be in control and not open to making changes in management and lifestyle • The need to feel that they are making the decisions • The need to limit engagement with health services

	• Viewing management as being told off • Using what has been termed 'propaganda' to demonstrate understanding of the consequences of diabetes in a bid to keep doctors "off their back".
Peer Support	• The need for peer support to be organised to accommodate similar people groups, similar age ranges • The feeling of comfort being around those experiencing similar issues • Surprised to feel the benefit of peer support, which previously had not been considered • The feeling of not wanting to disclose blood glucose results which then deters them from engaging in peer support • Avoidance of peer support
Support person/partner involvement	• Supporters' 'desire to learn' and identified learning needs, versus those of their partner/support person • Partners' need for information/education regarding complications and emergency situations • The change in parental involvement moving from child to adult services • Conflict between patient and support person regarding involvement in their diabetes, which can cause resistance • Positive support and person/partner involvement
Theory/Practice Gap	• Ability to describe problem solving but inability to put theory into practice • Not self-monitoring or taking insulin as they should but understanding and relaying what they should do
Need for education and access	• Length of time living with condition does not always determine knowledge and expertise in management, leading to assumed knowledge which may not be there or out of date • Bureaucracy/red tape affecting those who can and cannot attend education • Long waiting lists for education • Access to education limited to levels of numeracy and literacy and certain geographical locations • No formal 'support person education' • The need for education to be personal and individualised • Education is a diabetes priority area
Health services	• Gaps in knowledge and expertise in diabetes in general health services where diabetes is not the specialty or remit • Shared care with hospital service and GP; appointments often not coordinated to allow regular review, sometimes patients see both in close

	proximity and then have a long period of time with no review
	• Are HCPs doing enough to point out long-term risks associated with diabetes?
	• Reviews are sometimes viewed as tests or a tick-box exercise
	• Poor engaging with health services or collaborating with HCPs
	• The feeling of being patronised by HCPs
	• The need for hospital services to support new technology, complicated by health service processes (inability to download device results and set up the iPads for education)
	• The need for continuity of care and continuity of HCP
	• Lack of communication affecting patient empowerment
	• Conflicting information/advice
	• Not all patients understand their targets or goals
Frustration of living with diabetes experiencing abnormal/unexpected results	• Not understanding what has gone on when they see less than optimal results.
	• Frustration and confusion affecting confidence and empowerment
	• Realisation that problem solving has gone wrong
	• Loss of control (feeds back into control)
Focus on HbA1c rather than real-time blood glucose results	• Real time blood glucose readings and HbA1c do not always portray the same picture
	• An individual may experience results that are not optimal and suggest poor control but are reassured if HbA1c is at a reasonable level
	• HbA1c is seen as the key variable and the focus at review
Focus on avoiding LOW blood glucose levels/fear of hypos	• Managing levels higher than recommended upper limits due to a fear of hypos
	• Understanding low levels, what they feel like and how to deal with them. Not having the same physical recognition or understanding about the management of higher levels and the risks associated with higher levels
	• Problem solving focused on diet and reluctance to adjust insulin doses
Superficial SMBG	• Reacting to abnormal levels rather than preventing them
	• Taking actions too late
	• Doing what they are told in terms of testing but not actually engaging in the management
	• Documenting results but not analysing them

	• Reacting to abnormal readings but not problem solving or acting in a sensible way in response to the results • Relying on the physical feeling of abnormal blood glucose levels to inform actions, which is often too late • View SMBG as self-management • Viewing SMBG on its own and not related to management
SMBG fitting in with life – a chore	• Difficulties or reluctance SMBG when out socially • The problems of carrying monitor when out • Change in routine affecting change in monitoring and control • Forgetting to monitor or take insulin when out • The need to factor in the time required to monitor and the time for taking actions prior to going out anywhere • The need to continue enjoying certain lifestyle choices; social bonding • Habitual nature of SMBG – doing the same thing but never achieving desired control or cure

Re-reading and further analysis of this cross-case comparison allowed a typology of self-management to be developed with each individual categorised according to a type of self-manager. This typology is detailed below:

6.4.1 Typology of Self-monitoring Behaviours

Certain types of self-monitoring practices and behaviours were noted. These have been grouped into three categories and listed below. Each case participant has been identified as falling into at least one category. Some participants display features of different cateogries at different imes.

Short-term monitoring: *Angus (with very limited long-term characteristics), Tam (also in sporadic), Brian, Pauline, Peter*

Although these participants recognize the importance of self-monitoring, rating it around 10 out of 10 when asked, they do not appear to be confident in problem solving and rate their confidence in self-management lower than importance; at around 7out of 10. For this reason their testing involves little problem solving and generally involves looking at the number and dealing with the immediate problem in the short term, with little consideration of the reason

for the abnormal result, future energy demands over the day and how this can be prevented in the future.

These individuals tend to be nervous about adjusting insulin levels, generally due to this lack of confidence, and they are not keen to consider changes to their management. This appears to have some link to the fear of hypos which often stems from a previous bad experience.

In certain cases individuals are of a higher education level and have the knowledge in this area but this knowledge does not match their ability to problem solve. Many do not take their testing equipment out with them socially and therefore only test when they are at home.

These individuals report the physical signs and symptoms experienced when blood glucose levels are lower than normal limits, but are unable to detect signs of blood glucose levels being too high. In turn they tend to run blood glucose levels which are higher than normal, which appears to be due to their fear of hypos and the fact that they have an awareness of when levels drop too low. They generally have little concern regarding high blood glucose levels.

Some in this group tend to enjoy partaking in lifestyle behaviours(smoking, drinking and poor diet), which can affect their glycaemic control and are aware of and acknowledge this; testing is then sometimes used to identify how much these lifestyle factors are pushing their limits beyond normal levels and to allow them to control this to a certain degree.

They often document their SMBG results; sometimes just in the week or so before a review, but there is little analysis of the results.

There is reporting of reasonable HbA1c levels, although SMBG levels are often outwith normal limits.

Some of the self-management practices within this group are undertaken automatically without pre-thought.

This group generally don't feel a need for further education, and don't think there would be anything else to learn.

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They refer to not wanting to dwell on their diabetes and several of the partners in this group identify a need for further education in diabetes, especially in relation to emergency situations and the risks associated with the condition.

Long-term monitoring: *Maureen (limited level), Alison (significant level), Bill (limited level)*

This group monitor with a longer-term plan and an attempt at some kind of problem solving. They consider future energy requirements over the rest of the day, prevention of abnormal readings, and some exploration of patterns.

There appears to be forward planning when they are going out with regard to taking monitoring equipment out with them and how they are going to facilitate this.

All appear to engage in support from their partner/support person and are not adverse to peer support.

There is a feeling from these participants that they view their diabetes as 'part of them'; rather than a condition they have.

Sporadic monitoring – just now and again: *Michelle, Tam (also in short term), Charles*

Like the short-term category, this category consists of individuals who are of higher education level and have the knowledge but this knowledge and intelligence does not match their ability to problem solve, as well as some who do not take their testing equipment out with them socially and therefore only test when they are at home.   Two of the participants refer to their diabetes not being in their head and forgetting to take insulin.

This group does not tend to document their results. There is reporting of reasonable HbA1c, although SMBG levels are often not within normal limits.

Self-monitoring does not seem to rate as high in terms of importance within this group, one participant rating confidence higher than importance. Another views HbA1c a much more important indicator than SMBG.

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Like the short-term monitors, this group run blood glucose levels above the recommended levels to avoid hypos and have little concern regarding levels being high.

The typology of self-monitoring behvaviour was then considered in conjunction with each key thread. Re-analysing by refining these second-order constructs and considering how they connected together and matched with the type of managers, considering unanimous areas of agreement, contradictions and paradoxes. This was done through amalgamating the thread, the case, then type of manager and the supporting evidence, in a final cross-case analysis. Throughout each stage of the analysis process there was an awareness of how metaphors may be used and consideration for the numbers of participants within this qualitative process. Conclusions were tested through the constant contrast and comparison process. This also included the noting of relationships between variables as well as the partitioning of variables; when differentiation is more important than integration (Miles et al. 2014).
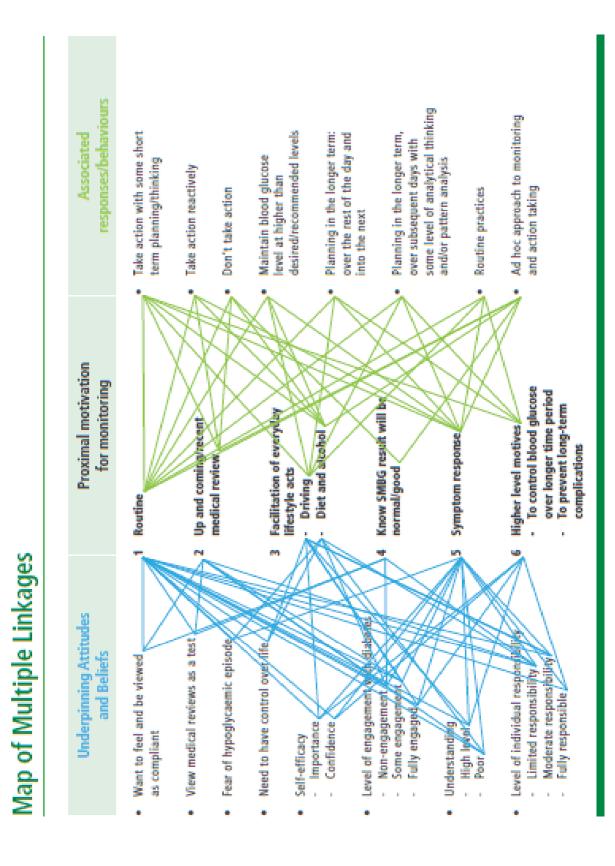
6.5 Cross-case comparison

The results of the cross-case comparison identified three higher-level layers:

1. The proximate motive for monitoring:
   This is the immediate motive for why an individual monitors; the motive for why they monitor at a certain point on a particular day.
2. Associated responses/behaviours:
   This is the subsequent action or behaviour that the individual undertakes following monitoring.
3. Underpinning attitudes/beliefs:
   This is the basis from which the proximate motive arises and in turn the associated actions, and assists in explaining these behaviours.

It is important to note how each of these three areas interlink and move across and how each area influences the other, which is by no means a linear process. Analysis of the data and mapping of the results has uncovered that there may be multiple possible behaviours/responses for an individual motive, and likewise the motive may be influenced by a variety of attitudes and beliefs. Yet

it is the relationship between these concepts which can assist our understanding of why individuals behave the way they do in relation to self-monitoring.

The following figure illustrates the factors identified within each area and how these interrelate, which will be discussed in detail in the following section.
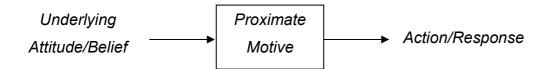
Figure 4: Map of Multiple Linkages

Map of Multiple Linkages

This chart lists the proximate motive for testing, along with the possible responses and behaviours, and the underpinning attitudes and beliefs identified in this case study. Multiple linkages were noted between each concept and are demonstrated in the chart. These linkages came together in different combinations.

It is clear that there are multiple different linkages across the three layers and some have been represented through the participants of this case study. Also, the same participant might display different combinations of linkages at different times. However, it is important to bear in mind that there may be other types of permutations not illustrated on this chart.

Discussion of this final analysis is provided below and is structured in six sections. Each one addresses the proximate motive. Each section firstly describes the motive and then explains the actions and behaviours demonstrated in relation to that motive and then goes on to discuss the underpinning attitudes and beliefs relating to the motive.

Proximate motive for monitoring

<u>1. Routine</u>

The Motive

This motive addresses the type of monitoring which forms everyday practice and is either specific to a certain point within the day, that is, related to meal times, or simply a routine process to allow them to report results to HCPs.

> *I take it as soon as I get up in the morning before I do anything.*
> *(Angus)*

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> *I take it before meal times and as my husband does the cooking he will shout me a few minutes before he dishes up and asks if I'm ready, and this means, 'Have you checked your blood sugar?'*
> *(Alison)*

There is a degree of routine motive for testing for most participants, with the exception of Charles, who reported testing sporadically without any routine nature to his self-monitoring.

> *It's not like I can say, oh well once or twice a day or something like that regular, I can go for 7 weeks, or maybe not quite as long as that without using it at all and then I'll have to use it 4 or 5 times a day.*
> *(Charles)*

As this is a routine process, for some it was reported to be undertaken with little thought. The routine nature of some patients' testing was noted to be something that was very ingrained and built on past experiences and there was a feeling that, for some, there is no way they would consider changing practices they have undertaken for many years.

> *Aye this guy's an old hand you see, he's been type 1 for 45 years and he's fairly set in his ways.*
> *(Podiatrist Colin)*

The Action/behaviour

There was a range of associated actions in relation to routine monitoring, including: No Actions, whereby those who test may or may not document the result but then take no action based on this result. There were Reactive Actions, which were immediate actions involving little thought; usually glucose or carbohydrate intake or the administration of insulin. Short-term Actions were also noted in relation to this motive: actions whereby some thought was given to the SMBG result and required response, for example, carbohydrate intake or insulin taken for future energy expenditure. Some Long-term Actions were also noted: involving a level of analytical thinking in relation to this motive. Long-term Actions involved consideration of the type and level of action taken, rechecking the effect of actions and consideration of future carbohydrate intake and energy expenditure over the rest of the day and into the next. Analytical thinking was defined as moving beyond the long-term thinking to question why

blood glucose levels move to the levels they do, looking at results together in the context of their life and lifestyle and analysing this over several days.

Testing and documenting results may be routine, but for an assigned period of time. This is usually requested during a review when the HCP is seeking to gain a better understanding of the patient's glucose control.

> *Look, we need to work out why this is happening here, why this reading is not as good as the last time or whatever, you'll need to write down things, for two or three days (laugh, laugh) or a week, you know (laugh), because people don't.*   *(Dietician Sally)*

Behaviours in relation to this motive tend to include testing at certain points in the day and/or are associated with mealtimes. Routine testing for most is undertaken in the home situation with some participants stating that they never or very rarely take self-monitoring equipment out with them. Routine testing undertaken outwith the home was only noted by three participants: Alison, Maureen and Bill.

There were two participants who admitted to often taking no actions following testing and this was more so in relation to higher than normal blood glucose results. An example is Tam, whose routine testing is mainly influenced by compliance and attempting to keep HCPs happy through the provision of results, regardless of the stability of these results. Tam was aware that HCPs are not happy with his level of control, as he notes in his self-monitoring results.

> *'Cause they were'nae happy with me when I was there the last time the time when I met you … eh … they were'nae happy with me then, with the scale of it going up an doon.*   *(Tam)*

But he appears to see the provision of his results as conforming to some degree and therefore making up for his poor control.

Tam's actions in relation to results were noted to be reactionary; although he did occasionally document his results, there is no thought in terms of problem-solving actions or preventing abnormal blood glucose levels. In saying this, he only appears to be able to reactively manage when levels fall too low.

> *If it's high … there's no really … anything you can dee … it's already there.* (Tam)

Reactive responses to routine testing without consideration of other factors or more prospective planning are also demonstrated by Michelle and Brian. These were usually observed in relation to additional physical symptoms and are therefore discussed further in the 'Symptom response' section.

Short-term actions were associated with routine testing, in the cases of Pauline, Maureen, Peter and Angus, who all demonstrate some thinking and planning around the actions they took and for the facilitation of their immediate activities, for example, going to work, working in the garden or playing golf. However, there were no 'longer-term' thoughts or analysis. Both Angus and Pauline speak about an intention to go back and consider/problem solve or apply more analytical thinking to their result, sometimes marking these results in their diary, but invariably they never get round to it.

> *If there was something wrong then I might mark it, so that I could look at it, again, but invariably I don't; I've taken so many, that I really have become blasé … as long as the numbers at that point are, you know, but it's an immediate response and a … oh phew … you're no too high.* (Angus)

HCPs noted the many different approaches to self-monitoring employed by their patients.

> *… and it's massive, massive range of difference, because there is a massive spread of personalities across and some levels of obsessiveness.* (Podiatrist Colin)

Dr Whitby refers to the different types of actions in relation to routine testing and categorises two types of testers: those who test because they are told to test and those who test to self-manage. She refers to this limited problem solving when discussing Pauline's self-monitoring and associated self-management.

> *She neatly documents them all but then doesn't always do an awful lot with them.* (Dr Whitby)

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Dr Whitby suggests that routine testing without problem solving is a result of poor understanding.

> *Frequently people understand that monitoring itself is important and sometimes it seems to me that they are really conscientious in terms of blood glucose monitoring, some might do it you know several times a day … but they don't understand what they are meant to do and how they are meant to use the results, so sometimes it seems to me they don't quite understand … it's like there's a disconnect between their understanding of how important blood glucose monitoring is, what to do with the results they get and why that's important in regard to minimising risks of long-term complications, sometimes patients understand all these things independently, but they don't quite manage to connect all this up.   (Dr Whitby)*

The general opinion from HCPs is that most patients understand that self-monitoring of blood glucose is important but that this importance does not link to the relationship between self-monitoring, good self-management and reduction in risks associated with diabetes.

> *Everyone thinks they are invincible and that problems won't happen because of how they manage their diabetes, they will happen to other people.   (Dietician Sally)*

It was noted that many participants felt that they were an expert in diabetes, self-monitoring and self-management, due to the length of time they had lived with the condition. However, HCPs seem to feel that understanding around self-monitoring is not linked to the length of time the person has had the condition and note that many patients had out-of-date practices and information.

> *There doesn't seem to be a correlation between having lots of practice at this stuff makes you good.   (Podiatrist Colin)*

It was also acknowledged by HCPs that self-monitoring and how to apply this to self-management is not easy to understand and that patients need to have a certain level of numeracy and literacy to understand and apply this theory. This then restricts the suitability of some educational programs for all patients. It was noted that selection for education is often undertaken during clinic visits and is based on interest as well as individual ability to understand concepts

around self-monitoring, thereby restricting this access even further and often not including those who are most at need.

Other barriers to education also noted by HCPs, for example Dr Hay and Dietician Sally, are the limited number of places available on such courses and the timing usually being during work hours for most individuals, who may have difficulty getting time off to attend.

There was some long-term and analytical thinking described in relation to actions following routine testing. This was evident in Alison and Bill's case; these participants do test routinely but spend time thinking about and following up on test results in a variety of ways. Alison describes how she starts to problem solve and forward think/plan, as soon as she has pricked her finger.

> *Already I'm thinking, well if it says, whatever the result is, well I'm having that for tea, so therefore what'll mean, em, or I'll go and do, I'm going away out and or exercising, so if it's that, then I'm eating that and I need to cut back on the insulin because of that later.*
> *(Alison)*

For these longer-term planners, the thought process starts early in the self-monitoring practice, as opposed to those who are routinely monitoring with shorter-term and reactive actions whose thought process will kick in when they see the result and will not extend past the immediate action required.

Underpinning attitudes and beliefs

One of the underpinning attitudes associated with routine testing was the perceived need to be compliant. This was noted in Tam and Michelle's case, with Michelle referring to viewing reviews as a test; this is discussed in more detail within the 'up-and-coming/recent clinic appointment' section.

For some, routine testing was undertaken only for the purpose of presenting results.

> *I think that some patients see self-monitoring as something that has to be done so that they can present it when they come back to clinic, because there are patients like that … There are still a lot of people out there that do it because they've got to show something when they come back to clinic, em they make no changes based on the*

> *number that they see, just write down the number; they forget about it and it's gone.* *(Dietician Sally)*

As previously noted, routine testing was influenced by the view that SMBG is important in terms of overall self-management. It was noted that Charles, the only participant who did not routinely monitor, viewed HbA1c as being the more important marker and this therefore appears to be the reason why he does not routinely monitor.

> *I mean the key measure is always HbA1c, that's the target, I've always been encouraged to consider it the target variable.* *(Charles)*

It may be that those HCPs who are overseeing Charles' self-management are unaware of his lack of insight into its importance in his overall self-management.

Continuing this theme, the level of importance that individuals apply to SMBG in relation to reducing risks associated with diabetes appear to influence levels of self-efficacy. This seems to encourage confidence to more actively plan in the long term, analyse results, and generally engage with their condition.

Routine testing was also associated with routine practices around self-management. For example, Alison and her husband have a routine whereby he warns her five minutes before meals are ready to allow her time to test, and Angus keeps his testing equipment beside his bed to remind him to do so on waking and going to bed at night time.

Routine daily practices were noted to be a facilitator to the individual being able to undertake routine testing. Michelle reports having a limited daily routine of self-monitoring now and suggests this to be a reason why she currently pays less attention to routine testing.

> *I used to, so in High school, it was a routine, but now I don't have a routine, so it's really difficult even with meal times so it's in different places and having different meal times so …* *(Michelle)*

Less attention to routine testing also appeared to limit any long-term or analytical attention to test results and associated self-management practices, evident in particular with Michelle and Tam. It was noted that short-term and reactive thinking in relation to routine testing is also linked to patients taking less responsibility for their condition. This reluctance to take responsibility was also noted by one of the participants who could see other diabetes patients around her who were not taking responsibility for their self-management and reverting back to doctor-led diabetes management.

> *I know a lot of people who say, 'Well I have to wait until I ask the doctor before I change anything,' well actually that's not the case, it's up to you to know.*   *(Alison)*

In summary, all but one participant demonstrated routine testing and this was influenced by a variety of factors which included the need to comply for hospital reviews which was associated with less engagement and taking responsibility for their condition and in turn resulted in superficial reactive and short-term monitoring. On the other hand, those who were influenced by the importance of routine testing in terms of prevention had a noted association with engagement in their condition and individual responsibility for managing their diabetes. This was associated with higher levels of self-efficacy and influenced more long-term planning and analytical reasoning.

2. Up-and-coming/recent clinic appointment

The Motive

There was a noted change in behaviour around self-monitoring and associated self-management prior to or straight after a diabetes review. The changes in behaviour included an increase in frequency of testing, commencement of testing, or paying more attention through documenting results and actions taken in relation to these results. Two participants explicitly state that this was a key motivation for monitoring; Tam and Michelle.

> *Yes, yes … (giggle) … Yeah so maybe in the week running up to an appointment, I probably do more testing than I should be because I'm trying to almost work harder to have these where they should be so they are not seeing results way down at the bottom or way up at*

> *the top, so, I just pray they don't go too far enough back to see the*
> *other ones … (giggle) …*   *(Michelle)*

It was also noted by HCPs that documented results presented at clinic visits are usually the results taken in the week or so preceding the review visit when patients are generally being more careful with their self-management. There is an awareness that what is being presented is often not a true picture of glycaemic control.

> *I think that some patients see self-monitoring as something that has*
> *to be done so that they can present it when they come back to clinic,*
> *because there still are patients like that.*   *(Dietician Sally)*

> *Maybe the two weeks prior to their visit to the clinic may be different*
> *to normality … well, yes ... so in the patient's view, they will be*
> *'behaving themselves', but I'm just wanting them to act like they*
> *would always act and let's get a dose of reality, so we know what we*
> *need to be doing, but I think sometimes the patient will behave*
> *differently if they know that an appointment is imminent and they are*
> *staring to check where they wouldn't have checked particularly*
> *before, that's a possibility isn't it, it sometimes happens that way.*
>   *(Podiatrist Colin)*

The Action/behaviour

There was a noted difference in associated actions between the two participants who admitted to this motive. Michelle refers to trying harder (through testing more regularly and thinking more about associated self-management) to obtain better results at time periods relative to appointment times. As noted in the previous quote, this results in Michelle presenting a picture of her control to HCPs which is not a true or normal presentation. She talks about her fear that HCPs will look further back through her monitor readings and discover the true picture of her glycemic control.

On the other hand, Tam still does nothing, and his main objective is to present completed diary pages at his review but with little thought regarding the stability of these readings.

> *I do stop writing it down, for a particular reason as ... I would like to*
> *get at least the last page going up to the hospital at the time, you*
> *know, at a time ...*   *(Tam)*

Tam does not appear to associate testing with the aim of achieving glycemic stability and therefore this does not influence any change in terms of actions. He accepts that he will be in trouble with those overseeing his diabetes for the extremes of deviation from the norm in his control. This further illustrates feelings of being judged; the hierarchical/paternalistic model of care where patients feel they are being 'told off'.

This motive to test appears to prevent any long-term planning behaviour and was linked with more short-term and reactive actions; Michelle and Tam were also noted to take 'no actions' at times. These participants admit to sometimes intending to take action but for some reason they then forget to follow through with this action, that is, to inject the insulin.

> *… (giggle) … ah it's usually, just an "Oh, I've done the test, I've calculated the dose and I've not taken it' … (giggle) … Or sometimes it's like one pen's run out, so you've got to go and get another one, but by the time you've gone and got it, you've forgotten, you've forgotten what you're doing (giggle) …* (Michelle)

> *… but there is … you do forget sometimes … I even forget sometimes to inject myself.* (Tam)

Underpinning attitudes and beliefs

Michelle's ultimate drive in relation to this motive appears to be that of gaining approval from HCPs during clinic appointments. In addition to this she refers to having a fear of being "found out". She works on improving her control for a very short period of time but these efforts do not form part of her everyday self-management. This may be because her reason for making these changes is time-limited in relation to her medical appointment, rather than a means to achieving longer-term better health outcomes. This may be why, although Michelle says she wants to improve her control at these times, there is a general lack of engagement with her condition. This noted non-engagement with the condition is alluded to repeatedly by Michelle's mum.

> *… because of this whole thing of not wanting to identify with her diabetes … or … you know.* (Michelle's mum)

Disengagement appeared to push Michelle's diabetes far from her mind and may be the reason that she forgets to take actions. She describes her diabetes as being: "out of my head" (Michelle).

Tam also demonstrates disengagement with his condition, which may be the reason that both participants admit to forgetting to take important required actions following testing.

The disengagement noted in both participants is also linked to a reluctance or avoidance to gain further information and understanding or to explore diabetes in any depth. HCPs also refer to this issue, noting difficulties in engaging the patients who need it most in education, in particular, younger patients.

> *Another problem we have is getting young people to engage with it is sometimes quite difficult, I think they feel that it's a bit of a chore to go through the educational program and eh they are often the sort of people that you need to get there and then rather than having to say, 'Well there might be a session available in kind of three months' time, that you can go to,' because by that time, they've lost their drive to engage with us, so I think our access to this type thing is not good enough, and to those who would find it most helpful.*
> *(Dietician Sally)*

Exploring this further, Michelle and her mother refer to her avoidance of discussing her diabetes control in close detail or analysing patterns. Michelle's mum also notes her daughter's lack of desire for more knowledge or information about her diabetes. Michelle may have a fear that, once confronted by these issues, she will then have to seriously deal with them, rather than her current situation where 'ignorance is bliss' to a certain degree; what she does not know she does not have to deal with seriously. This may be further facilitating her disengagement with her diabetes.

Tam, likewise, demonstrates a reluctance to spend too much time considering his diabetes, its implications and how this could or should affect his self-management. He is content to have fairly irregular contact with health services and he also refers to not wishing to go into his condition in too much depth.

> *Well ... there's sometimes, like with the likes of … I would say that he's needing to be at the doctor's more ... in my own opinion I could*

> *see him seeing somebody, you know, I know he wouldn't like to see them because I know what he's like.* (Tam's partner)

> *I mean, this can happen or that could happen … I already know that, I don't know of anything else you need to know.* (Tam)

Other underpinning attitudes and beliefs linked to this motive are, as discussed in the previous motive, the need to feel and be viewed as compliant and to gain approval. This is influenced by participants fearing being told off:

> *Cause they were'na happy when I was in the last time, in when I met you, eh they were'na happy with me then, with the scale of it going up and doon ...* (Tam)

as well as viewing reviews as a test that needs to be passed:

> *… but every time you go you feel like it's a sort of test, that you've got to pass.* (Michelle)

The desire to gain approval through the presentation of results almost makes up for or deflects from the disapproval they may receive due to their poor glycemic control, which has resulted from ineffective or poor self-management. This disapproval, which they sense from their HCP, at times influences a negative view of HCPs. This appears to reinforce and deepen this disengagement, which thereafter moves into a vicious cycle of disengagement, affecting approval, and then reinforcing disengagement.

This feeling of disapproval by HCPs is also referred to by Carol, while she interprets her daughter's view of moving between HCPs during reviews.

> *Because they are moving between each one [i.e. HCP speciality] who wants to have a go at them.* (Carol: a mum)

The result of this perception appears to be an underlying resentment related to health services, particularly regarding the review process. There was a sense of an absence of flexibility with health service reviews and the feeling that these reviews are a tick-box exercise.

However, from the HCP's point of view, there are many constraints affecting what they can do and what they can offer patients due to resource issues, for

example, the education offered and the breadth of patient types that it can reach. Resource also appears to be an issue in relation to the prescribing of testing strips; diabetes consultants report that other health services may be restricting the amount of testing strips prescribed to the patients they are managing, which therefore affects the frequency of testing for these patients.

> *I think sometimes that primary care don't always understand why our type 1 patients are monitoring as frequently, there's a lot of you know attempts to ration strips and not having them doing as many tests and I think that there's a lack of understanding about the importance of that for enabling the patient to do the day-to-day monitoring and self-management, so I think there's a gap there that we need to make that clearer why we've asked them to do as many tests as we have.* *(Dr Hay)*

This suggests a need to raise awareness within relevant health services regarding self-monitoring and current recommendations relating to how often this patient group needs to test. Data from this study also noted that some HCPs were unfamiliar with the clinical guidelines around diabetes management and self-monitoring, even those working within diabetes services. When asked about the guidelines around self-monitoring of blood glucose, Dietician Sally responded:

> *Oh, I don't know, I have to admit (laugh, laugh, laugh) ... eh ... I really don't know, are there any?* *(Dietician Sally)*

There were several references made to a lack of understanding and awareness around diabetes self-monitoring and associated self-management from HCPs working in general areas where diabetes care is not the focus. This often results in the provision of conflicting advice as well as in-patient incidents related to patients and these affect their confidence in health services.

> *We find that there usually is an issue with blood glucose monitoring when people are in hospital, so not being tested enough or results not acted on appropriately.* *(Dr Whitby)*

> *Hospitals are not really set up for people to self-manage.* *(Dietician Sally)*

> *We have tried to improve the flexibility for people who are self-managing but it is not always easy.* *(Dietician Sally)*

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This rigidity within health services and lack of flexibility was also referred to in relation to the potential integration of technology into diabetes care. The health region where the HCPs were interviewed does not have the facility to download meters and then look at patterns as other health services can.

We can't because the IT setup here won't let us.   (Dr Hay)

In addition to this, there were difficult obstacles reported for using new technology for diabetes-related education. For example, the diabetes specialist dietician ordered iPads to use as an educational resource but she was unable to access the NHS iTunes account to set them up (despite several attempts to do so). So, she has been unable to add the apps required to set up the education and therefore hundreds of pounds in technical devices are sitting unutilised. These examples highlight the difficulties with NHS firewalls and high levels of computer protection against software which is preventing practitioners from utilising new technology to support patient education and to analyse management data.

In summary, an impending clinic appointment was noted to be a motive for testing which is also associated with changes in behaviour, including giving more attention to testing and self-management. However, the actions taken by those who change practices around clinic appointments tend to be more short-term actions, thinking and analysis. Those who demonstrate this change in behaviour in testing for clinic appointments are noted to be those who are less engaged and responsible for their condition, viewing contact with HCPs as a test which needs to be passed.

3a. Facilitation of everyday lifestyle acts - Driving

The Motive

The ability to drive and continue driving was a very strong motivator for testing. This motive was generally related to personal safety as well as the DVLA reporting requirements, which stipulate that patients with insulin-treated diabetes should test their blood glucose within two hours of driving and then every two hours when driving. If the blood glucose is below 5mmol/l, patients

are required to take carbohydrates, and if below 4mmol/l, they should not drive. If patients have experienced a hypoglycemic episode requiring assistance in the preceding 12 months this also needs to be reported to the DVLA and there may be an associated period of time when the patient will not be allowed to drive. This motivation was noted in seven of the cases.

> *It's not just in a sense the food that take, it's the activities that you join, it's the em ... the driving.* *(Angus)*

> *Well the main reason I do it is because I still drive.* *(Bill)*

> *Basically, if I know I'm going to be going out driving, I give it a check eh because I know that's very important.* *(Peter)*

The Action/behaviour

There was a wide range of associated types of actions undertaken by each of the individuals demonstrating this motive. Types of actions ranged from reactive, short-term actions, usually in relation to keeping glycemic levels from dropping below the required DVLA levels, but there were also long-term planning actions reported. There was also a noted tendency to keep levels on the upper side of normal which for some meant maintaining blood glucose levels above those recommended. For example, Angus refers to the need to control his levels when he is traveling to see relatives or going on holiday. His priority is to prevent a hypo and he therefore eats extra carbs on his journey to push levels up above normal to allow this.

> *… like at least two points higher than usual, and it's, it's sort of, if you like a self-protected mechanism, that I'm making sure that I don't drop on the drive down.* *(Angus)*

It was also noted that this motive places more attention on testing and associated self-management practices. This was particularly noted with Michelle, who admits to normally struggling to pay attention to testing and to remembering to take required actions relating to results. Michelle's mum noted an improvement in her daughter's attention to her diabetes when she was required to have stable blood glucose levels for driving.

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> *The driving took her to test and think about her management … but she's not driving so much now.* (Michelle's mum)

Underpinning attitudes and beliefs

Underpinning attitudes and beliefs for this motivation revolve around the desire to have control. This control allows the individual to do the everyday things they enjoy, therefore allowing normal life functioning. This in turn influences confidence and appears to be linked with improved levels of self-efficacy. For example, Pauline refers to being able to drive which then allows her to work, thus providing her with independence which can influence self-efficacy.

> *Just because it's so much easier to control your life … I have to do it before eating and before driving, so it has to be over 5 to drive, and because I do drive quite a lot obviously for work, I'm taking mine a bit more than the average person is.* (Pauline)

On the other hand, Maureen had temporarily had her driving licence revoked due to unstable control, when her blood glucose levels dropped below the required DVLA requirements. Because of this she is now dependent on her husband for transport. Here, poor control has affected Maureen's independence, and there was noted and reported lowered confidence exhibited by Maureen, which may be affecting her overall self-efficacy.

> *The reason I did it is because I started driving, so I first started driving, it would be what about 12 years ago … I had actually been having a lot of lows, so sort of, so I've now not got my licence … now I would say before I felt really confident, but the last year, I've been having a lot of problems due to my diabetes, so I don't feel as confident as I did before.* (Maureen)

This motive was associated with all levels of engagement with diabetes noted across the participants; so those who were fully engaged tested before driving, for example, Alison, as well as those who were less engaged, for example, Michelle. This motive was also linked to different levels of individual responsibility for their condition. Interestingly, Michelle generally displays a very limited level of individual responsibility for her condition but will test and take actions in relation to driving, although Michelle does not have a regular requirement to drive. On the other hand, Alison displays high levels of

individual responsibility which extends to her commitment to maintain glycemic control for driving for work, social and leisure activities. This requires Alison to invest significant thought and planning into the longer term, to allow her to do this. Alison comments that she actually recognises that this personal responsibility is a key factor in effectively managing diabetes and talks about those who do not apply this but instead blame something or someone else, commenting: "It's always someone else's fault or someone else's responsibility" (Alison).

HCPs also identified that there needs to be a strong motivator present to encourage patients to test and apply test results to self-management appropriately.

> *In terms of motivation to test then it's the people who want to improve their control, em who will test, em those who want to keep their driving licence.* (Dr Whitby)

3b. Facilitation of everyday lifestyle acts – Diet and Alcohol

The Motive

This motive addresses how some individuals use SMBG to allow them to undertake certain lifestyle acts, specifically the ability to eat and drink what they want. Tam, Charles, Brian, Pauline and Michelle all refer to viewing self-monitoring as affording them the confidence to eat and drink what they want, particularly the types of food and drink which do not form part of the recommended diabetes dietary plans. Charles states that one of his motives to self-monitor is: "if I fancy a dessert or something" (Charles), while Michelle refers to doing this retrospectively:

> *I eat something, so that makes me think … you should go and test now (giggle) …* (Michelle)

Again, here Michelle gives a nervous giggle, which indicates a sense of embarrassment at admitting to not managing her diabetes as she should be.

The Action/behaviour

Responses to this motive tended to be more short-term and reactive with little planning/thinking. The usual responses being those of adjusting insulin doses in response to the intake or merely regulation of their dietary intake. There were some reports of taking no actions at all but simply using the tool for peace of mind that control is not too far beyond recommended limits, as noted in Brian's diary extract:

> *Day 2:*
>
> *Before evening meal=14.2 … this is ok after 2 pints of beer,*
>
> *Most enjoyable*
>
> *Day 3:*
>
> *Before evening meal=16.4 … that's ok after 4 pints of beer,*
>
> *Well it is Saturday … I can live with it … let's see what happens tomorrow*

Underpinning attitudes and beliefs

As with the driving motivation, this motivation is also underpinned by a need to have control over their life: "It's giving me control" (Pauline). Pauline talks about how, before she was diagnosed with coeliac disease, she was able to eat anything she liked through the use of SMBG.

> *It's so much easier to control your life, because you have the choice, and until I was diagnosed with coeliac, I could eat absolutely anything I wanted, as long as I took the carbs to match there was no limits whatsoever, you're like normal with diabetes, you could eat absolutely anything you wanted. So if you just had diabetes and you were doing this self-monitoring, you're life's not different, well you know what I mean.*   *(Pauline)*

So, rather than her viewing SMBG as aspect of self-management, she views it as something which allows her to live life in the same way as those without diabetes do. This was also noted when Pauline rated SMBG 10 out of 10 for importance; the reason for this high rating was that it provides her with control

over her life. Therefore, she views this as a positive aspect, which appeared to provide a sense of empowerment for her.

This motive is linked to lower levels of understanding in terms of problem solving. Although Pauline understands the importance of SMBG, her high rating was due to the control it afforded her, which does empower Pauline, but there is little long-term reduction of health-associated risks underpinning the motive observed among the other participants. This may be a contributing factor in Pauline's difficulties in self-managing her condition effectively. It was noted by her HCP that she does not always appear to put theory into action in terms of decision making regarding her SMBG results.

> *She gives the impression of understanding what is going on and what she should be doing in relation to self-management but she doesn't always then put it into an actual action plan for her.*
> *(Dr Whitby)*

Dr Whitby also explains that Pauline often needs help to interpret results and what to do next. Therefore, the importance of obtaining control through this motive is not associated with effective self-management actions but appears instead to influence short-term and reactive thinking. The absence of longer-term thinking is also noted when Pauline talks about her intention to re-check blood glucose levels following actions relating to an abnormal results but she confesses that more often than not she forgets to do this. Thus, she understands some concepts of longer-term thinking and actions but does not seem to be able to apply them.

The desire to live life normally and be in control is a common theme for many participants and is strongly exhibited by Brian, particularly when questioned about targets. He makes it clear that he will not be dictated to and refers to the length of time he has lived with the condition and how he knows his condition better than anyone.

> *It's my body, right, with eh, the tools and the information that I've got, already, then it's up to me to manage my body and that's what I'm trying to do, using that diary and the meter I manage much better, I'm not saying I'm managing it perfectly, but I'm managing it to my*

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> *satisfaction ... and I'm happy with that ... If you can understand that.*
> *(Brian)*

Brian acknowledges that he is viewed as non-conforming in terms of diet and lifestyle and is happy to accept this. He uses SMBG as a tool for reassurance to allow him to carry on with the lifestyle practices that he enjoys. He is aware that what he is doing is not what is recommended and uses the word "rebellion" to describe this. Brian takes some comfort in the fact that '*he*' is the one ultimately in control and not HCPs. Again this creates a negative view of HCPs; suggesting a 'them and us' situation, which may be affecting engagement with health services and therefore with diabetes management.

> *I suppose that's my little bit of rebellion; like wanting to be normal (laugh) … and there's nothing they [hospital clinic doctors] can do about it (laugh) …* *(Brian)*

In a similar way, Tam realises that HCPs are aware of his non-conformance with diet and other lifestyle factors.

> *Well, well, stopping the drink for a start, well I've already been through the stuff about not having too many sweet things, which I don't really, but I have occasionally, right, chips; I just have chips when I want, I mean, it's no, right, I'm maybe no supposed to be, but I dee eat chips and things like that. But eh, eh ... but they, there isna really much else and dietary things that you can, you know you can look at it ... but that's aboot it really.* *(Tam)*

Tam reassures himself that there is not a lot he can do about his lifestyle in relation to self-management other than looking at the numbers. This behaviour and attitude, exhibited by Brian and Tam, is recognised by HCPs, who are well aware that these individuals are happy to live with the consequences.

> *He quite simply doesn't want to change, he's happy with the way his diabetes is controlled, eh, he's happy with the way he can function … it's his habit to socialise with his friends at the pub between 4 and 6pm (laugh), he doesn't want anything to distract from his quality of life.* *(Podiatrist Colin)*

As alluded to previously, this attitude seems to stem from a need to feel normal and the same as others within their peer group. This concept is recognised by HCPs and noted by Dr Whitby when commenting on diary extracts.

*He sees his actions as 'common sense actions' again a feature of
longstanding diabetes, many habits and beliefs are ingrained … he
comes across as feeling that if he cannot continue this ritual of a
couple of pints, he will lose control. Patients do not want to be
different from their peers and feel that they should be able to partake
in drinking like everyone else can.*

(Dr Whitby comments on Brian's diary)

The desire to feel normal and no different from anyone else appears to affect
some participants' engagement with their condition and is linked with a strong
level of non-engagement as well as limited individual responsibility. This is
noted in particular when Pauline was asked about goal setting with her diabetes
self-monitoring results. She talks about just getting on with life and not dwelling
on her condition.

*… but it's great just getting on with life (laugh) and not worrying
about it too much … I don't dwell on it, I just get on with it. And then I
go [to the hospital clinic], they sort me out.*   *(Pauline)*

Here Pauline is handing over responsibility for her condition to medical staff and
seems to consider that spending too much time contemplating her blood
glucose levels would be dwelling on her diabetes. She uses the term "dwelling
on" her diabetes several times throughout the interview, highlighting her need to
feel non-constrained by her condition.

*I mean I don't dwell on my diabetes, in that I would be looking at it
every day, you know, I mean, I wouldna do that.*   *(Pauline)*

The desire to be the same as peers, referred to previously, also seems to
initiate a resistance to peer support. This was referred to by Tam, Michelle and
Carol's daughter.

*I mean I know a couple of people that are diabetic and I dinnae go
and talk aboot it with them, you know it's no really eh, I don't think it
would benefit me.*   *(Tam)*

This motive is also linked to resistance to support people, particularly when
support people attempted to provide advice. This is again linked to 'control',
whereby participants experienced what they deemed as a form of control
through their support person's involvement. Angus talks about this when

describing not paying attention to what his wife advises him regarding diet. This is also noted when both Michelle's mum and Carol talk about exclusion from involvement in their daughters condition.

> *I had to kind of get a grip and kind of step back because you know I think she got so fed up with me continually asking her if she's taken her lantis or done this or done that, you know.*   (Carol: a mum)

Resistance is strongly demonstrated and referred to repeatedly by Michelle's mum when she talks about her struggles with no longer having an involvement in her daughter's condition and management.

> *The more I ask the more she gets angry … and she's 19 now so … erm … I (sigh) … I really don't know …*   (Michelle's mum)

It was also noted that, for those supporters who felt resistance to involvement in management from the person they were supporting, there appears to be a need and desire from that support person for information and education. It may be that this resistance influences patients to prevent or withhold access to important information from their support people. Tam's partner wanted more information regarding emergency situations, which Angus's wife also mentioned, along with the long-term health risks associated with diabetes and specific dietary information. Michelle's mum and Carol also feel a need to have more information on long-term complications and to be kept updated on current diabetes management.

The previously mentioned need to be in control and not be controlled, noted by some participants, was also noted to generate feelings of resentment, which may explain some of the resistance behaviours identified in relation to this motive. For example, Angus gives the impression of feeling controlled by the repetitive nature of his SMBG, having to do the same thing, time and time again. He presents the procedure as being painful to him in terms of monotony as well as the invasive nature of it. He appears to resent the chronic nature of the condition from which he can see no end.

> *Having to virtually do the same thing on a daily basis over something like … now I'm 75, so 18 years, well it's really a pain in the ass if I*

> *had to say … so I don't find many positives actually, it has to be done and that's it.* (Angus)

Although Angus tests regularly there is resentment about the control that testing has over his life. This appears to be related to him seeing no end point in terms of resolution around his management. On the other hand, he benefits in terms of the control that SMBG can give him through allowing him to continue playing golf and partake in other lifestyle activities. He sums this up by describing it as a "mixed bag":

> *Yes it is, at times it's a real inconvenience, but at other times it's just part of it all ... it's like a mixed bag.* (Angus)

In summary, there was a strong motivation to test to allow participants to undertake everyday lifestyle acts. Specifically, driving was underpinned by a legal requirement and therefore influenced individual responsibility for patients' glycemic control. This required some level of action-taking, ranging from short-term to more long-term thinking and problem solving.

Facilitation of other lifestyle acts included SMBG to allow individuals to eat and drink what they wished while observing blood glucose levels and thus fostered a perceived control. As well, the underpinning need to be in control was linked with this as there was also a need not to feel different from peers. However, this was also linked to low levels of responsibility, poor understanding and produced short-term actions or no actions with little or no problem solving.

4. Know SMBG result will be normal/good level

The Motive

It was noted that some patients test their blood glucose at a time when they know a stable blood glucose reading is most likely.

> *So it's almost like, you know a kind of pattern of testing at the same time … almost … yeah … almost when it's, it's fine … yeah I don't know, it's a peculiar thing.* (Carol: a mum)

When considering those who test when they know their blood glucose will be within the desired range, this was also linked to these individuals then not

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testing when they suspect results will be far from the desired range; those who do not test because they do not want to know the answer.

> *There are other patients who will avoid monitoring at times when they know that it's going to be an abnormal result, because they don't want to deal with it.*   *(Dr Whitby)*

> *… they don't want to do it because they don't want to know what the answer is, so actually the result scares them.*   *(Dietician Sally)*

The Action/behaviour

There was no specific response behaviour to this motivation, as a stable blood glucose reading generally requires no action to be taken and, likewise, for the times when actions may be required to be taken, these individuals do not undertake testing. Michelle and Carol's daughter were both reported to test in relation to this motive.

Underpinning attitudes and beliefs

The underpinning attitudes and beliefs again appear to be associated with these individuals wanting to conform to a certain degree to allow them to gain approval from HCPs. As noted in previous sections, there is an underpinning negative attitude towards health services, which in turn affects those individuals' engagement with health services. For example, Michelle's mum talks about her daughter viewing health services and reviews as "surveillance", which, in her opinion, has had the effect of pushing her daughter to disengage with services and her diabetes. Her mum then goes on to explain that Michelle's diabetes reviews are not an enjoyable experience but something she wants to get over and done with as quickly as possible.

> *She goes in and she gets out again as quickly as she can … it's not a collaborative experience, it's not a supportive experience, it's a 'you've got to go there once a quarter,' or whatever, I've just got to go in and I've got to get out, that's all it is … she tries to get out as quickly as she can.*   *(Michelle's mum)*

Similarly, Carol believes her daughter views assessment of her blood glucose as surveillance and, similar to Michelle, this triggers her daughter to then

disengage with her diabetes management. Carol refers to the challenge of getting her daughter to attend reviews and provides several examples of resistance to engagement. For example, her daughter was asked to trial a device but refused. Carol feels that this was due to her daughter's reluctance to allow her results to be viewed and judged.

This low level of engagement with their condition, noted in Michelle and in Carol's daughter's cases, is also associated with feelings of self-consciousness in relation to their condition and, again, this need to not be different from peers. This was noted when Michelle talks about the discomfort she feels when her self-monitoring device makes a beeping noise when she is out in public.

> *… because it's really like people look round and they go, 'What's that beeping, something's happening.'* (Michelle)

This raises the issue of the process of self-monitoring being difficult to undertake discreetly. This is compared by several participants to the process of injecting insulin, which was noted to be more easily undertaken when not drawing attention to yourself.

> *If you think of an insulin pen … I mean pens are so discreet aren't they, you just turn the dial and quickly pop it in and you know it can all be hidden by a coat or a jumper can't it … whereas the whole you know testing kit, it's a bit of a palaver compared to that isn't it … you have to get it out in the open, you've got to fiddle with the strips and sometimes you have to do the finger prick twice.* (Carol: a mum)

This need to undertake diabetes self-monitoring discreetly and feeling self-conscious was noted to be linked to age. Michelle's mum talks in detail about how her daughter was not self-conscious in the least when she tested as a child but that this has developed with age. Therefore, it may be that a child sees testing in public as making them 'special', whereas as they move into later teens and adulthood, this changes to the feeling of being 'different'.

As identified in the previous section, the disengagement was not limited to health services and was also noted in relation to peer support. Michelle talks about being put off formal education as she is not keen to be in a group and having to disclose her blood glucose levels.

She appears to have a fear of being the only one who has poor control and gives the impression of wanting to hide her level of control. This may be affecting her level of empowerment, which can in turn affect self-efficacy. The terminology that Michelle uses to describe her blood glucose results also implies that she views this as a test where she is being compared with others who may be achieving a much better "score" than she is.

> *You had to write down all your scores and they went round the room, which was 'ah no!'…* (Michelle)

In spite of these feelings, as noted in the first-level analysis, Michelle actually benefits from being pushed into this peer situation. It appears that it is difficult for individuals to understand the potential benefits of this type of support until they are actually in the situation. This is also recognised by Carol:

> *An interesting thing with this; that if you don't feel like you need support, then you don't want it … do you know what I mean.*
> *(Carol: a mum)*

This suggests that because it is difficult for those individuals who are actually in need of peer support to recognise this themselves, those most at need are not seeking help or are not receiving the most appropriate type of support.

As noted previously, this motive is also linked to patients then not testing when they know their results will not be in the desired range. Dietician Sally refers to those who do not test because they do not want the answer and patients who avoid monitoring at times when they know they will get an abnormal result, noting that one of the underpinning reasons is that they may not be able to deal with the results at that time.

> *… so they actually don't bother doing it, because it's easier than dealing with the numbers they are going to get.* (Dietician Sally)

So, being prepared for abnormal results and the provision of time to deal with results is an important factor which may also influence patients' testing.

> *It gives you an answer maybe that you don't want, because actually you don't want to know that you're less than 5, when you know you've got to pick your child up from gymnastics in 10 minutes,*

because you can't, you've got to do something about your diabetes
first (laugh). *(Dietician Sally)*

In summary, testing at times of glycemic stability was noted as a motive to test, and this was also linked to non-testing at times of glycemic instability. Due to testing at times when no action is required and not testing when action is required, this generally led to no active response. The underpinning attitude appeared to be the previously noted view of surveillance by overseeing medical systems, and again this was linked to a disengagement with services and thereafter the individual engagement in their condition and responsibility for managing their condition. Allocation of time for testing was also an important factor in terms of the ability to deal with results.

5. Symptom Response

The Motive

All participants are influenced to test in response to physical symptoms. In general, the symptoms most likely to initiate testing are those related to low blood glucose, with most participants reporting that it was more difficult to pick up physical signs of high blood glucose.

You can actually feel it as well you can feel when you go doon,

Eh … no so much when you go high like, it's more when you are
going doon to 2 or 3, you can actually feel it … within yourself … I've
never had anything when it goes high, I've never felt oot of sync or
that when it's high … but in the mornings when it's low … you can
feel it, but as I've said, it's gone up to 30, I don't feel any different.
(Tam)

… and if it's high there's not really much other than tiredness.
(Angus's wife)

It was noted by Dr Whitby that, for some patients, physical symptoms are the key self-indicator of glycemic control.

There are a group of patients who do very little monitoring and claim
to know their blood glucose level just by how they feel.
(Dr Whitby comments on diary extracts)

Thus, this suggests that physical signs may be inhibiting patients from self-monitoring as they come to rely on physical signs.

The Action/behaviour

Those who tested in relation to physical symptoms usually undertook some form of action following testing. Actions ranged from being reactive and short-term, to longer-term analytical thinking.

For some this is the main motive for testing and, when this is the case, it generally initiates reactive actions, for example, as Michelle describes:

> *I'm most sort of … pushed to do a test when I feel something's not quite right, but I then need to find out how high, so you find out what you need to do to correct that. So they are the main reason I would test.* (Michelle)

Michelle then goes on to explain that any thinking in relation to testing is usually too late and that there is not any forward planning in relation to her testing and associated self-management.

> *It's always more later on, so I should really check beforehand just in case.* (Michelle)

The physical symptoms associated with this motive were noted to be unpleasant and to generate a feeling of fear. Some participants described how it is the unpleasant nature of these physical signs that influence them to take actions and for some this results in them maintaining blood glucose at levels higher than those recommended to further minimise the risk of this occurring. Three participants referred to managing their diabetes at blood glucose levels that far exceed normal levels: Tam, Brian and Charles.

> *If I eat something and say it shoots into double figures, which is not unusual, around 12 to … 19, that was exceptional, I don't know what 20 feels like.* (Charles)

It was noted that these participants in particular are much more concerned about blood glucose levels dropping, than them being above normal.

> *I'm more frightened about it going doon, than I am about it going*
> *high.* *(Tam)*

Although these participants do understand that there are also longer-term health risks associated with blood glucose levels being maintained above normal, it appears that it is only the immediate physical feelings of low blood glucose that influence actions. This was noted to be due an overwhelming fear of the immediate risks associated with a hypoglycemic episode where individuals had experienced altered levels of consciousness.

> *… it scares the shit out of me … I don't want to have another hypo,*
> *right, I don't want to!* *(Brian)*

Here again there may be a link with the feeling of not being in control during hypoglycemic episode that some patients refer to. This fear of blood glucose levels dropping to dangerous levels was also transferred to support people, two of whom commented that they felt a need for more information and guidance on what to do in emergency situations.

In addition to requesting more information regarding emergency situations, support people were also concerned about the long-term risks associated with diabetes and felt a need for more information and to learn more about this.

> *I would like to know more about the breakdown probably of his skin*
> *and the nerve endings and the feet; this sort of thing. I don't really*
> *know much about and it is just, 'Well this is what happens,' so I*
> *would like some more information about that, but maybe it's all there*
> *and I haven't looked at it.* *(Angus's wife)*
>
> *I would probably like to know more about the side effects and what to*
> *look out for, em ... cos no so much about the diabetes but the side*
> *effects what to look out for so I can see, so I can see if anything is*
> *going wrong.* *(Michelle's mum)*

It was noted that those whose actions were reactionary in relation to physical symptoms and that those who did not problem solve with more long-term planning appeared to lack confidence in adjusting their medication.

> *Sometimes people with a high reading will opt not to eat and take the*
> *insulin to bring down a high reading, rather than consider the amount*
> *of insulin they need to take in the future to avoid the high readings in*

the first place. Patients with longstanding diabetes were educated at a time when insulin dose adjustment wasn't something we recommended and we tended to dictate what the solutions were rather than encouraging patients to self-manage which is what we do now. (Dr Whitby comments on diary extracts)

HCPs referred to feeling the need to 'switch on' problem solving in some patients. The general consensus was that it tends to be the patients who lack confidence who do not problem solve and these patients often have limited understanding with some guesswork going on.

There was limited use of new technology to assist with self-management with the participants in this study. It was noted that many had devices that had lots of functions and features which some individuals reported to not understand how to use. There was a sense that devices were given to participants without the support to allow them to use the features to their full capacity.

Underpinning attitudes and beliefs

For most, the key underpinning attitude for this motive was focused around a dislike and fear of unpleasant feelings associated with the physical symptoms of low blood glucose. This contrasted with the notable lack of personal awareness of blood glucose levels being higher than the desired levels. This was noted by Dr Whitby, who points out that it is the absence of immediate danger with high blood glucose that makes it easier to ignore.

> *People have a fear of hypos because of the neurological symptoms, risk of unconsciousness and need for third party help if it's severe. They are less concerned with high readings and frequently don't check for ketones or take corrective action with insulin. They are not as symptomatic with highs and block them out, especially the risk of long-term complications … I think it's easier to ignore something that doesn't have an immediate adverse outcome like a hypo.*
> *(Dr Whitby)*

All levels of engagement were associated with this motive. As alluded to in the actions section, there were noted differences between levels of engagement and associated responses; those who were fully engaged with their condition demonstrated more long-term and analytical thinking in relation to the

symptoms, in contrast to those who were less engaged and who demonstrated reactionary and more short-term responses.

The poor engagement and reactionary/short-term response to physical symptoms was noted in particular with Michelle and Tam, and, as described previously, the underpinning poor engagement is referred to frequently by Michelle's mum.

> *They just don't seem to get the engagement from her to get her to do as well as she could.* *(Michelle's mum)*

Michelle's mum felt that the crucial point in time where this engagement is lost is the transition from child to adult services.

> *… and it's an absolute disaster, I don't know how many conversations I've had with parents in the waiting room … that children are just not old enough to manage the diabetes and frankly not old enough to have the conversations with the consultant or the nurse, because they don't know the questions to ask, they don't know what to do.* *(Michelle's mum)*

Engagement loss at this time was also noted by Carol, who can also pinpoint situations which affected her daughter's engagement with services and her diabetes. She refers to the negativity that ensues when an adolescent girl has to spend her Friday afternoon sitting in a diabetes outpatient clinic while her peers are all out socialising:

> *… and she sat in the diabetic clinic for the afternoon, you know, I mean, granted it doesn't happen very often … but it's another barrier to wanting to engage with services, you know.* *(Carol: a mum)*

> *… because at the end of the day it ends up being a 10-minute consultation doesn't it.* *(Carol: a mum)*

As with poor engagement, there was also noted lower levels of personal responsibility linked with the reactionary and shorter-term thinking in relation to this motive. This was noted through reluctance to manage their condition, for example, through the adjustment of medication; for some, management involved only reacting to low blood glucose results with many not even recording results.

> *You'll get a diary if you're lucky, or maybe a piece of paper but mostly not.*   *(Podiatrist Colin)*

In summary, symptom response was a key motivator for all patients to test. However, this was mostly in relation to symptoms associated with low blood glucose levels and was generally due to a more heightened awareness and unpleasant feelings associated with lower blood glucose as well as a fear of hypo. Although this motive influenced many types of actions across the spectrum, from reactive to more long-term thinking, there was a link between some participants maintaining blood glucose levels in excess of recommended limits with the underpinning fear and discomfort related to hypoglycemic episodes. This motive was associated with all levels of engagement and responsibility related to their condition.

6. Higher level Motives

The Motive

This final section addresses the immediate motive to test being due to higher-level and longer-term reasoning. Such reasoning includes:

- To control blood glucose levels over a longer period of time
- To prevent long-term complications

Three participants demonstrated higher-level motives to differing levels: Alison, Maureen and Bill.

The Action/behaviour

This motive always involved taking actions when required with some form of problem solving and reasoning. This ranged from action taking with planning over the rest of the day from Bill and Maureen, to longer-term thinking and planning with some analytical thinking from Alison.

Forward planning was associated with this motive, for example, allowing time for actions and facilitating the carrying of testing equipment.

This motive was also associated with following up on actions, whereby individuals would self-monitor following actions taken to check the effect of the action on their blood glucose.

In contrast, those who did not demonstrate this motive rarely followed up on results after testing, although there was awareness that this is what they should be doing.

> *Yes, you should come back and see if what you have done has been the right thing … Sometimes I do, but not a lot … (giggle)…*
> *(Michelle)*

There was a clear awareness of goals or targets in relation to self-monitoring from those who demonstrated this higher-level motive. Those who did not have this higher-level motive appeared to view goals as a notion referred to during consultation with HCPs but something that is not really achievable in reality.

There was reference made from one HCP to the importance of individualising goal-setting, including an individual assessment on how much information they can assimilate: "It's not one size fits all" (Podiatrist Colin).

This suggests that the goals set may not specifically take into account the individual, in the context of their own lives.

Underpinning attitudes and beliefs

This motivation was linked with a higher sense of engagement with their condition which influenced the participants' ease and facilitation of testing, particularly at 'any time and any place'. For example, Alison and Maureen refer to how they always facilitate testing through access to equipment and factoring in the time needed to take actions after testing. In comparison, those less engaged with their condition view testing outwith their home as a barrier and thus generally only test when at home. These participants, Michelle and Tam, generally do not facilitate or undertake testing when out. Michelle feels a need to justify why she does not test when out, stating that she generally does not carry a bag with her so would not be able to carry testing equipment. Michelle also refers to the time requirement for testing, explaining that university life is

not be conducive to accommodate the time requirement and routine necessary for self-monitoring: "everything just falls away" (Michelle). She does not appear to consider that she may be able to fit in and facilitate self-monitoring within this lifestyle.

It was noted that those who demonstrated this motive, and higher-level engagement with their condition, are less self-conscious about testing in public than those who were less engaged, who tend to demonstrate higher levels of discomfort regarding testing in public. For example, both Alison and her friend refer to Alison's openness and ease with self-monitoring wherever she is. However, Tam and Michelle refer to not feeling comfortable with this:

> *I dinnae dee it in company … I mean I don't take it with me, eh no, … I dinnae go out and do it, I don't take it with me.*   *(Tam)*

The higher level of engagement with their condition, noted with this motive, was also associated with an acceptance of their condition being part of them. Alison refers to this twice in her interview where she describes her diabetes as:

> *… it's part of me … I just want to see it as part of me, that's it you know (laugh).*   *(Alison)*

This was noted in contrast to those who were less engaged with their condition, who view their diabetes as being something which places them apart from everybody else and makes them different. This appears to be a factor which results in disassociation and resistance to engage with their condition.

Higher levels of responsibility were associated with this motive. Bill and Alison believe themselves to take their condition very seriously and both comment and make reference to others who do not take responsibility for their condition.

> *Ignoring it, it's stupid, I know folk that do that.*   *(Bill)*

> *It's just, it's, you know, I've got work and I've got my own things to do, kids – all be it, they're older now, em, you know and the greater scheme of things it's like (sigh) … but I'm the one that's responsible for it and nobody else can do it for me, I have to do it myself you know, em ...*   *(Alison)*

Bill also demonstrates a higher level of individual responsibility in his determination to make the lifestyle changes recommended for his diabetes. He talks about altering his lifestyle following his diagnosis and explains how difficult this was at the outset, describing getting used to new lifestyle factors as "strange". He then went on to refer to his previous experiences of making significant lifestyle changes following the diagnosis of a serious health condition when he was diagnosed with cancer and coronary heart disease. This implies that previous experience and practice of behaviour change may be an assisting factor in encouraging individuals to take more individual responsibility for future health conditions.

In contrast to previous motives which noted that poor engagement with diabetes was related to resistance to support person involvement, stronger support person involvement was noted in those with higher levels of engagement with their condition. This was noted most significantly with Maureen and Alison. Maureen's husband (her identified support person) was observed to be actively involved in her management, logging and charting her SMBG results and attending clinic visits with her. Maureen appears to welcome this support from her husband. Similar to Maureen, Alison welcomes support from her husband. She discusses how he does all the cooking and always considers her SMBG and associated diabetes self-management, calling her a few minutes before meal times to remind her to monitor. In addition to this, she refers to how she discusses her management with him: "He knows where I'm at" (Alison).

Alison's husband is not her only significant support person, she also has a supportive relationship with a close friend, who is her identified support person. Her friend provided a detailed account of the different actions Alison takes in relation to her management. It is clear from this that Alison regularly discusses her diabetes with her friend. Both Alison and her friend talked about her network of friends and how they all consider her diabetes when organising social events. There is a strong sense of openness and wide acknowledgement of Alison's condition with her family and friends. In contrast to this, those who were more reluctant to support person involvement

demonstrated a much less open attitude to sharing their diabetes self-management with those close to them. Even when referring to peer support, these individuals appeared reluctant to discuss their diabetes with their peers or to engage in peer support.

Higher levels of engagement were also associated with being better informed in relation to self-monitoring and associated diabetes self-management and there was a stronger desire to understand their condition. The differing levels of engagement in diabetes-related education were noted by Alison's identified HCP, who refers to those who have out-of-date information and the different levels of need for and access to education.

> *There's good quality education out there, some want it, some don't and as I say some don't have access to the things they want.*
> *(Dietician Sally)*

Access to education for all was also noted by Dr Hay as being a significant resource issue:

> *I just wish there was better access to it, it there are too long a waiting time, but that's because it's popular ...* *(Dr Hay)*

In summary, higher-level motives were generally related to a desire to achieve good, stable and longer-term control with the long-term aim of health risk reduction. This influenced more thought and consideration around actions with long-term planning, which involved facilitating and pre-planning testing as well as the required actions and follow-up after testing. Underpinning attitudes for higher-level motives were seen in those with high levels of engagement in their condition and individual responsibility with a noted acceptance of their condition, and acceptance of support person involvement. This acceptance extended to seeing themselves with their condition, rather than the condition making them different from their peers, which prevented feelings of embarrassment with associated disengagement.

6.6 Summary

The results of this case study have been analysed progressively, interpreting meaning through a constant comparative approach. An inductive approach

using an emergent framework based on theoretical principles has been used to group the data and the explore relationships.

The key findings have been presented as the six key identified motives to self-monitor. Firstly, the motive of routine was demonstrated by the majority of the participants with differing and wide-ranging underpinning rationale and associated actions. This ranged from those with low levels of engagement with their condition with little thought and planning relating to actions, to those at the other end of the spectrum; two participants who demonstrated high levels of responsibility for their condition with analytical thinking and long-term planning.

Secondly was the motive to test for an up-and-coming or recent medical review. This motive was strongly associated with lower levels of engagement with their condition and responsibility for their condition. Associated behaviours and actions included giving more attention to testing and management at this time but with little longer-term planning and analytical thinking.

Thirdly was the motive to promote the facilitation of everyday lifestyle acts. This motive was twofold: an association with driving, underpinned by the legislative requirements for driving with diabetes and thereby requiring a level of individual responsibility; and allowing participants to consume their desired dietary and alcohol intake while observing blood glucose levels at higher than recommended limits.

Fourthly was the motive to test when the individual believed their result might be at a good or stable level. This was associated with no action taking and an underpinning fear of failure and surveillance.

The fifth motive was testing in response to physical symptoms, which was demonstrated by all participants and mostly associated with the physical signs of low blood glucose. These were reported to be more noticeable and unpleasant than those of high blood glucose. This motive initiated a wide range of actions and was underpinned by a strong fear of hypoglycemic episode from those with all levels of engagement and responsibility.

The final motive was that of higher-level motives to control blood glucose levels over a longer period and/or to prevent risks associated with poor diabetes control. Here there was a strong desire to achieve good glycemic control and reduce the risk of diabetes-related complications. This motive initiated responses whereby the individual engaged long-term planning and analytical thinking.

The six motives laid out in the final analysis, alongside the underpinning reasons and associated actions, provides a picture of the varying complex attitudes and influences on this process which are not necessarily obvious on initial presentation.

On completion of the analysis the multiple linkages were viewed and considered in their entirety to allow higher level interpretation. This process involved reviewing and noting down the linkages for each of the participants, considering influencing factors and the possible rationales for actions. During this process key discussion points emerged, for example when looking across most of the linkage journeys, 'resistance' (discussion point two) was a key theme influencing self-management. The higher level interpretations were then summarized into five discussion points.

1. The relationships between individuals and their diabetes are linked to the level of engagement with their condition
2. Resistance was a recurring theme
3. Diabetes reviews are important and effect how individuals manage their diabetes and engage with their condition
4. There were noted gaps and limitations in knowledge and understanding around diabetes in patients, support people and healthcare staff
5. There was a noted fear of low blood glucose/hypoglycemic episode and this was connected to maintaining blood glucose levels above recommended levels.

The following chapter will address these five key discussion points emerging from this analysis, drawing on related literature to form a critical appraisal of the findings.

CHAPTER 7: DISCUSSION

7.1 Introduction

The research questions for this exploratory study sought to determine what individuals are doing in relation to SMBG in the context of their lives and the structures around them, and the perspectives of HCPs and support peoplein relation to self-monitoring.

This chapter is structured around five key discussion points emerging from the final analysis which relate back to these research questions.

Although sectioned into these five identified discussion points, there is some 'crossover' due to the fact that each point can interact with and influence others, which again highlights the complex interplay of factors evident in this study. Each point will draw upon relevant research which will then be assimilated to form conclusions and implications for research and practice. Following the five discussion sections is a short section which addresses the strengths and weakness of this study.

The first point addresses the different relationships that individuals have with their condition and how this affects their engagement with their diabetes. Point two refers to the resistance noted by individuals in relation to health services and their support people. Point three explores how diabetes reviews can affect individual engagement. The fourth point looks at knowledge and skills gaps around diabetes for the individual with diabetes, their support people and HCPs. The final point addresses fear of hypoglycemic episodes and how this can influence how individuals manage their diabetes. All five points address the first research question of 'what individuals are doing in relation to SMBG in the context of their lives and structures around them' but also moves beyond this to allow us to understand the complexities of the influences and interactions of the associated behaviours. The second research question is embedded in all five discussion points by providing additional understanding through the different perspectives of HCP and support people.

As noted in the analysis section structuration theory was integral as an analytical framework and also influenced the final discussion points. Discussion point one and two refer to individual engagement and associated resistance to their condtion. This was influenced by visualization within the structuration framework of the link between the demands of a chronic illness and differing levels of engagement or resistance. Discussion points two, three and four were influenced by the recognition in structuration theory that the management of a chronic condition must take place within different structures. For example, HCPs oversee the management of diabetes within health service internal structures, whereas patients self-manage in very different external contexts (or structures). Continuing this theme, structuration theory recognizes the importance of all the structures and agency relating to an individual and therefore 'the lived experience'. This influenced discussion point five: how patients are self-managing to fit with their own lives.

7.2 Differing relationships between individuals and their diabetes linked with the level of engagement with their condition

The participants within this study demonstrated differing relationships with their ucondition, and these different relationships appeared to be associated with their level of engagement with self-monitoring and associated self-management. For example, Michelle was unengaged with her condition and this affected her ability to apply longer-term thought and planning to her self-management. In contrast, Alison viewed her condition very much as part of her, demonstrating high levels of engagement, and this appeared to influence her long-term planning and self-examination of her SMBG results and associated management.

Within this study, engagement with diabetes was a concept which was noted across many key discussion points and it was not always clear whether it was the level of engagement affecting the relationship with their diabetes or vice versa. For example, was it Michelle's disengagement which prevented her from paying attention to testing and associated management or was it because she was no longer in the habit of testing that she became disengaged with her condition?

We know that poor control can make individuals less keen to engage in SMBG (Peel et al. 2007), which may include the undertaking of practices such as documenting, sharing and examining their SMBG results. This was noted in particular with Michelle and Tam who generally did not document results or consider and undertake required actions. Unstructured approaches to testing and poor collaboration with HCPs have been identified as factors that impede good glycemic control as it does not foster the sense of engagement that is associated with improved self-efficacy (Polonsky et al. 2011b).

Other factors associated with the individual's relationship with their condition were motivation and empowerment, which are the basis for self-efficacy. Michelle was noted to lack empowerment in relation to her diabetes self-management. Examples of this were her lack of confidence in her ability to apply self-monitoring to self-management effectively and her fear of having to disclose how she had failed in this self-management. In addition, she expressed a wish not to explore her diabetes, and diabetes in general, in too much depth. It may be that the less she knows about the condition the more her personal responsibility is minimised. In essence, she knows what to do with self-monitoring and has some intent to do this, but is not motivated to put this into action. Furthermore, her need to hide her self-monitoring results and not address her condition suggests she does not feel empowered in terms of her self-management. Lack of empowerment can also have an effect on self-efficacy and quality of life (O'Kane and Pickup 2009). This may be connected to Michelle's mum's reference to her seeking help with her emotional health when she talks about her daughter's appointments with a psychologist. Wu et al.'s (2013) survey sought to examine how depressive symptoms in young people affect family involvement in their self-management and concluded that even mild depression can interfere with parental involvement in self-management and identified the need for strategies to address depression within this group, which could then potentially facilitate parental involvement (Wu et al. 2013).

Empowerment is an important aspect of chronic disease self-management (Ho et al. 2010), but is not one which is easily understood in terms of how we can

achieve empowerment in diabetes management (Hood 2010; Khazrai et al. 2015). Patients who are empowered to be active participants in their diabetes are more likely to achieve good glycemic control and thus decrease their risk of developing diabetes-related complications (White 2012). Empowerment is something that has been difficult to define as it is an interconnected process based on how an individual feels about their condition and feeling different from others, as well as their views and beliefs (Hood 2010). For instance, an Iranian study noted that empowerment was particularly undermined if individuals felt embarrassed or wanted to hide how they self-managed their condition. This was noted with Michelle as she displayed self-consciousness around testing and consistently demonstrated behaviour (giggling) suggesting embarrassment regarding her diabetes self-management. This study also determined that an important stage in the empowerment process is 'the desire to learn', in other words, those who are less empowered have a lesser desire to learn (Abdoli et al. 2008). Both were features observed within this case study; as well as Michelle's demonstrated embarrassment about her diabetes management, those who were less confident in self-managing their condition, such as Michelle, Tam and Brian, were less keen to engage in learning more about the condition. This raises the question: does learning empower and then enhance a desire to learn? Or is it lack of empowerment that creates the vicious cycle? The findings from this case study would affirm both suggestions, thereby emphasising the challenge inherent in empowering some individuals.

Reviews have been undertaken to identify approaches that may be effective in empowering patients to effectively self-manage their diabetes. White's (2012) systematic review suggests that patient empowerment is achieved through a variety of means which extends beyond the provision of information and includes educational strategies such as interactive teaching and problem solving as well as individualised teaching (White 2012) but should acknowledge that individuals have different learning needs and styles (Hood 2010). Education will be discussed in more detail within section 7.5 of this chapter.

Empowerment was a factor noted to be important by the HCPs within this case study. There was an acknowledgement that patients need to be empowered to

self-manage their diabetes but it was evident that this was not the case for some, in particular, Michelle, Brian, Tam and Pauline. Ho et al. (2010) sought to gain a deeper understanding of what is important to facilitate empowerment in diabetes self-management through a meta-ethnographic review of qualitative research in this area. This study identified four central descriptors which affect empowerment: firstly, 'trust in nurses' competence and awareness', through their knowledge in diabetes and how they impart this to the patient. Secondly, 'striving for control'; this addresses the patients' coping mechanisms and their security, which are important elements of empowerment. Thirdly 'desire to share experiences'; this addresses how group interaction can be a key element in effective empowerment. Peer support and the support of partners and family members fulfilled the patient's need for emotional support and in turn enhanced empowerment. The last central descriptor was 'nurse's attitude and ability to personalise'. HCPs' attitudes to diabetes care encountered here were noted to affect empowerment, with reports of lack of concern, lack of empathy and coldness. The first descriptor, 'trust in nurses' competence and awareness', was referred to frequently in the study findings, with reference to situations where nurses, midwives and other HCPs did not demonstrate adequate understanding around diabetes. The second descriptor of striving for control was noted in those participants with low levels of empowerment: Michelle wanted to control what blood glucose levels her doctors viewed at reviews and also was reluctant to involve her mum. Brian and Tam were unwilling to make changes to lifestyle habits, which also appeared to be related to them maintaining control over their lives. Others, for example, Maureen, Angus and Charles, referred to the control that SMBG gave them to maintain and continue everyday activities. There was also a noted connection with the final two descriptors: Michelle, Maureen, Brian and Tam all demonstrated reluctance to engage in any type of peer support and there were several references to nurses' attitudes. Michelle's mum referred to a desire for continuity of care, an element that was lacking in Michelle's management, and the importance of individualised care, an element that is key to this final descriptor of personalising care.

The link between empowerment and control was identified by Handley et al. (2010), who explored the lived experiences of adults with type 2 diabetes in a New Zealand population group. Within the participants of this study there was an emergent need for ownership and control of their condition. The key themes raised during interviews with this group were: loss of control, gaining control and staying in control (Handley et al. 2010).

Lifestyle change is also a positive empowerment facilitator, whereby deciding to, or being successful at, lifestyle change is known to empower individuals (Ho et al. 2010) and, in this case study, Bill in particular talked about making such changes. This appeared to encourage a much more positive approach to his self-management, allowing him to forward plan, problem solve and analyse to some degree. Alison also demonstrated empowerment through her approach to her self-management, but, unlike Bill, she had learned to consider good lifestyle choices over the course of her life due to being diagnosed since childhood and did not need to make drastic changes. Yet, like Bill, she appears to thrive on maintaining healthy lifestyle choices and regular physical activity, which is likely to contribute to her empowered approach to her self-management.

Lifestyle habits most notably affected Tam and Brian's ability to effectively self-manage their diabetes, to the point that they no longer entertained the prospect of making any changes. The final analysis demonstrated that both Tam and Brian's underpinning attitudes resulted in a lack of individual responsibility for their condition. Lifestyle modification treatment has been used in some countries to address this public health challenge. A Swedish study assessed how lifestyle modification treatment can affect the individual's responsibility for their own health for patients with cardiovascular disease and type 2 diabetes. The results suggest that this type of treatment encourages the process of self-development, which enhances the individual's responsibility for their own health, as well as encouraging resourcefulness in accessing support. These authors conclude that lifestyle-focused group interventions can enhance self-efficacy for longer-term behaviour changes (Ljung et al. 2012).

As well as looking at facilitators to empowerment, Khazrai and colleagues (2015) explored other factors affecting empowerment and, in particular, refer to the relationship between empowerment and individuals having the necessary knowledge and skills to undertake the required processes. These authors noted the resource involved in empowering patients through knowledge exchange and emphasise the need for adequate training for those involved in the exchange process. Other factors include the implementation process for strategies to address empowerment within different types of health structures as well as the willingness of clinicians to pass on the power to empower the patient (discussed in more detail in the following section), and the willingness of the patient to be empowered (Hood 2010; Khazrai et al. 2015).

Self-efficacy, which has been defined in Chapter 1, has been said to be a product of empowerment in diabetes self-management, but again, the specific workings of this relationship have been difficult to understand and, in particular, to measure (Hood 2010; Khazrai et al. 2015).

It has been proposed that practice tools used to assist clinicians in the management of diabetes should include an 'empowerment element' but there also needs to be larger and longer controlled studies investigating how to achieve empowerment and whether it is a process or an outcome (Khazrai et al. 2015).

Levels of personal responsibility were noted to affect how individuals in this study engaged with their diabetes self-management. Investigation of this concept refers to this as the individual's 'Locus of Control' (LOC). Specifically, this relates to one's belief in their personal responsibility for their own health outcomes. There are two types of LOC: 'internal control', whereby the individual believes that they are in control of their own health outcomes; and 'external control', which refers to an individual's perception that they do not control their health outcomes (Rotter 1966). Both types of LOC were observed in this case study, for example, Alison and Bill were deemed to have an internal LOC, demonstrated in their strong sense of responsibility for their own health, which appeared to influence careful consideration of their self-management in the longer term with some analytical thinking and long-term planning in relation

to their self-monitoring results. In comparison, the remaining participants, those who demonstrated an external LOC and viewed that the responsibility for the diabetes was in the hands of medical services, were those who self-managed their diabetes with limited longer-term thinking/planning and analysis. This finding supports a recent study that analysed risk perception among patients with type 2 diabetes, which also noted that patients who were identified as having an internal LOC were more proactive in the management of their diabetes and emphasises the importance of concordance and empowerment for diabetes self-management (Macaden and Clarke 2010).

In summary, the relationship an individual has with their diabetes will affect how engaged they are with their condition and how they then engage with health services to manage their diabetes. Many factors where noted to affect the relationships that the participants in this study had with their condition, one of which was empowerment. Empowerment was noted to be related to motivation and self-efficacy and assisted participants to identify the importance of and ability to make necessary lifestyle changes.

7.3 Resistance: a recurring theme

The individual's responses to and co-operation with health services and HCPs is important in then determining their relationship with their diabetes and self-management. In a similar way, supportive relationships with friends and relatives are noted to have a positive influence on how patients self-manage their diabetes (Ho et al. 2010).

For some participants in this study there was noted resistance to both health services and support people, which appeared to subsequently prevent a collaborative process from occurring, and this is a theme echoed within the literature (Berg et al. 2011; Costa et al. 2012; Davis et al. 2007; King et al. 2014).

Michelle was observed to display significant resistance to both support person and health service support. Michelle's mum describes their relationship as being good on the surface, but feels that when she attempts to offer her daughter support she is perceived as "nagging", which then results in her

daughter pushing her away. Michelle's mum mentions that this issue was raised during a psychologist's meeting that both Michelle and her mum attended. Recent studies have identified the benefits of parental involvement in self-management, particularly in young adults, to allow higher diabetes self-efficacy (Berg et al. 2011; King et al. 2014). However, the benefits of such relationships are noted to be affected by the individual's emotional health (Wu et al. 2013), thereby raising the issue that it may be Michelle's emotional health which is influencing her lack of desire to be supported by those around her, evidenced by her mums reference to Michelle being seen by a psychologist.

Resistance is also about an individual's relationship with their body and diabetes. For Michelle, it is her body and she wants to resist control by others. One might argue that this is another form of empowerment.   It may be that Michelle uses resistance to allow her to maintain control. However, it could also be argued that resistance is a way of reclaiming some control over an 'out-of-control situation'.

Support people can play a key role in patients' management of long-term conditions and the role they play can change through the course of each patient's life and time living with their condition (Rankin et al. 2014). Positive partner support and involvement has been identified as being helpful in encouraging patient adherence with and engagement in SMBG and was noted in this study, in particular with Alison, whose husband played a role in her diabetes self-management through knowing where she is in terms of control, and reminding her when she needs to SMBG. Some studies suggest that those in a stable relationship are more likely to monitor (Costa et al. 2012; Davis et al. 2007). Nevertheless, it has been noted that such involvement should not impose such control that can then affect an individual's empowerment or self-efficacy (Costa et al. 2012; O'Kane and Pickup 2009). The balance of support and empowerment was a concept noted with Maureen. Her husband is noted to be very involved in her diabetes care, but this involvement appears to extend to the point of almost 'taking over'. Maureen comes across as lacking in confidence and it may be that this type of involvement makes Maureen feel powerless, thus affecting her self-efficacy.

The more collaborative approach with partners was noted in Bill's case who also referred to discussing his control with his partner and they attended some reviews together. This welcoming of support and collaboration appeared to enhance Bill's self-efficacy rather than inhibit it, but, ultimately, is it because the individual feels in control and they are allowing facilitation of collaboration? Those who demonstrated resistance often demonstrated a need for control, for example, Michelle and Brian. This is a very important consideration, as there was a significant difference noted in terms of outcomes between those who did not demonstrate resistance, and those who appeared much more in control of their self-management and were thus empowered in considering and managing their condition in the immediate and the long term.

Spousal overprotection has been studied by Johnson and colleagues (2015), who documented that spousal coping abilities can influence an individual's dietary adherence in type 2 diabetes and that spouses have different ways of coping with partner illness. But they also noted that little is known about how partner coping mechanisms link and interact, and then affect health outcomes for the individual with diabetes. These authors highlight the importance of understanding the intricacies of links between how spouses cope with partner illness and how this influences and affects the patient's behaviours in terms of their diabetes self-management adherence (Johnson et al. 2015).

The resistance to health services noted by some within this case study appeared to stem from negative feelings which had developed over time and was influenced in relation to various situations of engagement with services. For example, there were frequent references to medical reviews being seen as a tick-box exercise, long waiting times at clinics and lack of continuity of HCPs. It seemed that those who demonstrated resistance to health services did not view the overall medical management of their condition as a partnership with health services within which they could be an active participant. Some contrast with this was noted in those who did not demonstrate such resistance, for example, Alison described exchanges with clinic staff during reviews in more of a collegiate way. She referred to how she explores options with medical staff and receives positive feedback in relation to her efforts with self-monitoring and

self-management. Positive exchange with health professionals appears to foster more engagement and consideration of self-monitoring. The difficulty is how to break the cycle of disengagement and associated poor empowerment with low levels of self-efficacy.

How patients interact with health services is known to influence patients' compliance, satisfaction and health outcomes and the nature of this interaction has changed considerably over time. Patient views of medical interaction date back to the '50s and '60s when this was first considered. At this time, the advantages of the GP being the key interface were raised, the reason being that the GP could provide a more personal approach to medical interaction though knowledge of the patient and consistency of care (Seale et al. 2001). However, modern healthcare and primary care has now moved away from this 'family GP' model, with GPs no longer having such personal connections with their patients (Olesen et al. 2000).

Acknowledgment of the significance of the doctor–patient rapport in terms of patient compliance and satisfaction has led to further exploration of this topic and the development of different models of patient–doctor relationships, ranging from active-passivity, where the doctor treats and the patient is a passive recipient, to the mutual participatory relationship, where the patient and doctor are equal contributors in individualised medical management. The latter has been noted to be a model best suited to chronic illnesses (Kaba and Sooriakumaran 2007; Szasz and Hollender 1956), with recent reviews suggesting that patient empowerment is enhanced by medical staff taking on the role of advisor as opposed to manager (White 2012), the type of relationship that was reported by Alison.

The doctor–patient relationship has adapted and evolved over time. Up until the last three decades this relationship was based on the patient seeking help and the doctor making decisions that were passively accepted by the patient. Patient information was selectively provided to ensure patient consent. This paternalistic model, sometimes referred to as 'compliance', has been challenged over the last thirty years with the advent of active patient involvement in their care where there is a collaborative relationship with the

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doctor. Exploration in this area suggests that this approach requires the doctor to see the condition from the patient's perspective and from within the patient's world (Kaba and Sooriakumaran 2007), moving from the previous model of compliance to a 'concordance model'. This approach is based on respecting the patient as an individual and working collaboratively on mutual goals (Henshaw 2006). In summary, patients are clearly better informed and more involved with their conditions, especially those with chronic diseases who are now self-managing their condition. However, have physicians fully adapted to moving into the patient's world and understanding the condition through the patient's eyes? And are they willing to hand over their power? For some, this may challenge their professional role; these concepts have not yet been evaluated (Kaba and Sooriakumaran 2007; Khazrai et al. 2015).

Some participants within this case study, for example, Michelle, Tam and Brian, were noted to be affected by their relationship with medical staff, and this may have been due to the difference in expectations between patient and doctor.

It has been suggested that it may be the responses to an individual's perceived non-compliance that may be what triggers resistance to health services and health practitioners. For example, Michelle and Tam understood that medical staff were well aware of their non-compliance. This has been explored previously in a study that examined what doctors expect of their patients in terms of adherence to self-management (Wens et al. 2005). The GPs within this particular study identified their key challenges in supporting self-management; these included: deficient knowledge and understanding, reliance from patients on modern medicine, and not making necessary lifestyle changes. These challenges are reported to cause frustration, which often leads to a paternalistic attitude from the doctor and an ensuing non-collaborative relationship. Proposed solutions from the GPs centered on improving communication, alongside tailored and shared care. The development of these communication skills should be in relation to dealing with patient expectations and ensuring the maintenance of the collaborative relationship between patient and doctor (Wens et al. 2005).

As noted previously, the promotion of these solutions is also confounded because some doctors may have difficulty seeing the person, rather than the condition, and because of this they are unable to acknowledge the everyday implications of the condition in the wider aspect of the patient's life. The medical response to this may then go on to cause dissatisfaction from the patient's perspective (Seale et al. 2001). This notion was demonstrated in this case study where participants felt that reviews were a 'tick-box' exercise and therefore not personalised to the individual, which led to resentment from Michelle and Angus.

In summary, how patients utilise the support of health services and those around them is important in how they in turn self-manage their condition. Any relationship breakdown was noted to have an impact on their self-management. In addition, the important of balance in the supportive relationship was identified in allowing the relationship to be supportive and not constraining for the individual. This is equally important within the patient–support person relationship as well as the patient–HCP relationship.

7.4 Diabetes reviews

As well as some positive experiences and reports relating to medical reviews, there was also some negativity noted by participants when discussing reviews. A number of patients and their support people reported patient non-engagement with diabetes services and one of the reasons identified for this non-engagement was that patients found the review process an experience that resulted in feelings of frustration and negativity. These feelings were built on experiences which included long waiting times at clinics with limited flexibility in term of timing of appointments, the feeling that the review process is a tick-box exercise, that consultation and liaison with HCPs is not personal enough, feeling patronised by HCPs, and a lack of continuity of care or carer. The poor relationship with health services noted within this study appeared to then transpire into a chicken-and-egg situation. It is unclear whether it was the negative experience related to reviews which resulted in the poor engagement or the poor engagement resulted in reviews being a negative experience, or, perhaps, is this a constant chain of circumstances?

Research around patient engagement has raised the importance of HCP interaction. Eborall et al. (2015) explored experiences of self-monitoring following structured education through patient interviews. Patients reported lack of feedback or encouragement from HCPs as the reason for decline in SMBG (Eborall et al. 2015). As shown in this case study, those less engaged with their condition appeared to have poor relationships with HCPs, and this resulted in little attention being paid to their self-monitoring and its application of self-management.

Rodriguez (2013) noted that a patient's abilities and motivation to engage in self-management can be influenced by numerous intrinsic and extrinsic factors, some of which are proposed opportunities to tailor diabetes services in an aim to foster patient engagement. Recommendations within this article focused on entering the world of the patient, determining daily challenges, assessing individual priorities and motivators, establishing clear plans to allow for the necessary support systems, and address required changes to health systems which allow delivery of this patient-directed approach (Rodriguez 2013). This need to understand the patient's context was demonstrated in this case study by patients who kept blood glucose levels high so they could drive and who managed blood glucose levels to facilitate daily social activities, for example, Angus and Brian.

A UK study sought to identify the characteristics of patients who completely disengage from diabetes care using secondary data from a validated diabetes database alongside a systematic review. The results identified that those who disengaged were: significantly younger, experienced clinical anxiety and depression, had higher than recommended HbA1c levels, and were more likely to be male or from a more deprived area. The study also noted that those who disengaged struggled with self-management, thereby limiting their chance of receiving support to assist with their diabetes management. The study explored the possibility of applying interventions used to ensure compliance for other health needs, for example, text and phone call reminders for dental appointments. However, the authors concluded that the more deep-rooted complexities of chronic disease self-management would require a more

individualised approach (Elders et al. 2014). Within this case study some participants did exhibit difficulties with engagement and, although they were not completely disengaged with their condition and the health services, they may be on their way to disengagement. With this in mind, signs of disengagement should be a priority alert for health services to consider how to re-engage the individual.

Approaches to self-management education is an important factor to consider when trying to engage patients. Traditionally, teaching in the field of education, similar to medicine, has been very authoritarian, whereby the expert transmits knowledge to learner. The identified problem with this approach in patient education is that it does not allow for the clinician to understand and demonstrate their understanding of the particular condition in the context of the patient's life. When this occurs it enables an understanding of the condition and its meaning within the individual's life (Zubialde et al. 2007). Participants within this case study expressed the benefits of being with peers when learning, for example, in Pauline's case, when it allowed them to see what was happening in practice in other people's lives and allowed them to then normalise their own situation.

A US study applied an educational model used to engage adult learners, in a clinician and patient engagement situation. The study findings suggest that engaging patients in their care collaboratively, where appropriate and where the medical manager is less of technician and more of a coach, could assist with patient engagement, particularly for those with chronic conditions requiring self-management. However, this model has not been used formally within the medical setting other than for research case methods, therefore future research should formally test this model with other similar tools (Zubialde et al. 2007). Alison's management was an example of moving toward this type of approach.

It is well recognised that how patients view their condition will influence how they adjust their lifestyle and self-manage their condition. Therefore, it is important to understand patients' views if we are to encourage and promote effective lifestyle behaviours, diabetes self-management and compliance. A French study sought to measure GPs' understanding of their patients' illness

perceptions in relation to their diabetes (type 2). This large sample survey showed varied abilities across GPs to accurately represent the patient's view but there was an association between the GPs' understandings of their patients' perceptions of their condition and better self-care outcomes. The empathy demonstrated by clinicians in relation to patients and their diabetes was associated with positive health outcomes in patients along with increased satisfaction in care, trust and adherence (Sultan et al. 2011). The same finding was noted within this study; Alison felt that clinic doctors were empathetic to her efforts with self-management and that this in turn appeared to have a positive effect on Alison's engagement with her condition and health services. Empathy was also demonstrated in this case study by clinicians who accepted that patients would never change, for example, Podiatrist Colin referred to this in Brain's case, stating that his control was not too bad for someone who will not be changing their lifestyle habits. This can be compared with some of the other participants who had more negative experiences and views in relation to medical reviews, which appeared to affect their compliance and engagement. Sultan and colleagues (2011) suggest that medical staff should gain a good understanding of patients' views of their conditions, the condition's timeline and evolution, and how treatment can control the condition. This needs to be done through effective communication during consultations, therefore there is a need to explore interventions which can improve the interaction between the HCP and the patient (Sultan et al. 2011).

New technology and social networking have been identified as a possible way of engaging with patients (Kaufman 2011). A Facebook page is referred to, which attempts to engage with young people and provide information. It is targeted at those who do not attend services. Experience of this in other areas has been that engagement without an HCP can often encourage re-engagement with diabetes as well as re-engagement with services. It may be the feeling of surveillance that HCP input is noted to sometimes give, which makes this approach easier for these patients to re-engage. Although the participants in this case study did not specifically refer to this, several referred to the frustrating waiting time at reviews, for what some viewed as a 'tick-box' exercise and one support person suggesting a form of review with less face-to-

face contact. It may be that more quality of support or management could be provided by such means for some.

In considering other types of new technology, telemonitoring has been used to monitor aspects of chronic conditions remotely, and the use of this type of new technology has been studied by Hanley et al. (2015). This study explored the views of patients and HCPs where telemonitoring was used for blood glucose as well as blood pressure and weight in patients with type 2 diabetes managed within general practice. The qualitative findings reported the feasibility of using such technology in the management of diabetes and participants noted advantages in the convenience of using this method of monitoring and that they felt more motivated in their self-management. Conversely, HCPs had some reservations regarding the additional workload and cost that this type of management may produce (Hanley et al. 2015). These results, as well as the findings of this thesis, suggest that there is a need to provide a variety of methods to allow patients to self-monitor in ways that will allow them to feel more comfortable in revealing a true picture of their monitoring and control.

The pattern of patient behaviour changes linked to reviews noted in this study, whereby the patient consciously or unconsciously aims to trick HCPs into thinking that their control is better than it actually is, has been observed in other areas of health patient reporting. For example, there has been an awareness for many years that what a patient self-reports in relation to their alcohol intake and level of smoking is often not a true representation of the individual's lifestyle habits (Gorber et al. 2009; Midanik 1988). Clinicians are aware of this, as noted in this case study, and appear to accept this situation, yet this may not be the basis for a good relationship. Thereby, perhaps this is a concept which should be addressed when considering the building of trust between patient and doctor.

In summary, the interaction process between patient and health care services/HCPs is instrumental and has a 'knock-on' effect on how patients engage with their condition, self-manage their condition, and control their diabetes and health outcomes. Therefore, there is a need to more fully explore how we can influence and improve this interaction, moving beyond protocol and

guidelines but considering the individual as central and thereby avoiding this knock-on effect.

7.5 Gaps and limitations in knowledge and understanding around diabetes – patients, support people and healthcare staff

Education has been identified as being important to allow patients to achieve controlled blood glucose levels (Szymborska-Kajanek et al. 2009). There appeared to be several gaps in terms of understanding from patients, support people and also healthcare staff. Some of the participants could not remember whether they had been advised regarding the frequency and process of self-monitoring and what they were told. One particular patient could not recall ever being advised to SMBG or the importance being raised during reviews. The evidence also suggests that there does not appear to be a standardised approach to what patients are advised in relation to the frequency of testing as well as the actions to be taken following results (Karter et al. 2006; Polonsky et al. 2011a). In addition to this, a recent report has identified that, in England, only 2% of people newly diagnosed with Type 2 diabetes and 6% of people newly diagnosed with type 2 diabetes have attended a diabetes education programme (Diabetes UK 2016). Within this case study, only two of the participants had attended a formal education programme, a finding which supports these statistics and raises concerns about the uptake of formal education for individuals with diabetes.

It was noted, however, that diabetes and how it should be self-managed is a complicated concept and not easy for patients and their support people to understand. SMBG readings and the applied self-management have been reported as difficult to understand, especially large fluctuations from the norm (Peel et al. 2007). Within this case study, frustration, confusion and reduced confidence was associated with times when participants experienced self-monitoring results they did not understand. In fact, two participants were university lecturers and one a nurse with background experience in diabetes, and each had high levels of literacy and numeracy. Yet even these participants were struggling to get the application of self-monitoring to their self-management right. Therefore, HCPs need to be careful not to assume

knowledge and understanding in patients, and interventions to address poor understanding around diabetes self-management should not be limited to those deemed to have poorer literacy and numeracy skills.

Understanding around self-monitoring of blood glucose is imperative to an individual's self-management. Research has identified that it is not just the actions taken following testing but the 'problem solving' which is key to diabetic management through SMBG (Wang et al. 2012). There are limited rigorous studies exploring what problem solving advice patients are being given (Karter 2006; Polonsky et al. 2011b).

It is well documented that patients require a certain level of health literacy to effectively self-manage their diabetes (Nutbeam 2000), but as well as requiring skills in problem solving, there is also a need for patients to be analytical when considering their blood glucose results and associated self-management; it is not the regularity of monitoring and actions taken which are important, but rather the analysis to identify patterns and cues to lifestyle factors that encourages a patient to consider change (Linekin 2002). A Japanese cross-sectional study noted the importance of communicative health literacy and critical health literacy. The former considers the advanced skills required by patients to extract information and take meaning from different forms of communication in their diabetes care. It also refers to applying this to different situations and how the patient–physician relationship can affect this. The latter refers to the advanced critical analytical skills required to effectively examine blood glucose results and apply self-management. Both types of health literacy were linked again to self-efficacy (Inoue et al. 2013).

How patients with diabetes understand their condition has been associated with how they cope with living with the condition. Kneck et al. (2012) explored the impact of learning to live with diabetes through patient interviews and noted that how individuals experience and understand the physical body was of high importance in the learning process. Security in balancing bodily cues to live life was helpful, but the lack of trust in bodily cues affected independency (Kneck et al. 2012). This was noted within this case study in how some participants' fear

of low blood glucose episodes influenced how they self-managed their diabetes.

When the participants in this study were asked about understanding, many of them related the length of time living with their condition to a higher level of expertise in understanding and ability to self-manage. However, this was not evident in how some of these individuals self-monitored and self-managed their diabetes. Moreover, the link that some referred to between length of time living with the condition and expertise in self-management was disputed by the HCPs who were interviewed as well as evidence in this field, which suggests that it is the understanding of living with diabetes which positively influences an individual's ability to self-manage (Kneck et al. 2012).

Many participants within this case study referred to education programmes they had attended or were aware of and the literature also suggests there are numerous educational initiatives within the community that address different aspects of diabetes self-management. However, it is also noted that access to such programmes for all and for the people who actually need it is a problem. Structured education programmes have been shown to have positive outcomes in blood glucose control but there is little research on patient perspectives regarding the influence of such programmes on their self-management (Murphy et al. 2011). It has also been identified that these improvements are generally short-term, but for self-management principles to be improved over a longer time span, associated support is necessary. In response to a need for deeper understanding of the social context in which diabetes self-management occurs, Rankin et al. (2014) explored patient experiences and views of social support following the structured education program 'DAFNE' (Dose Adjustment For Normal Eating). Results from this qualitative study noted that course attendance prompted attendees to subsequently seek support from family, friends and/or colleagues, ranging from minimal support to seeking regular advice in relation to their self-management. It was also noted that an individual's use of support was influenced by personal circumstance. This study highlights the need for HCPs to gain understanding of patient support networks and how they operate in chronic diseases. This will allow HCPs to manage

their patients, educating and advising in the context of the patient's own life (Rankin et al. 2014).

Further exploration of the DAFNE education programme was undertaken by Murphy et al. (2011) to understand the factors which influence individuals to implement recommended self-management practices. The five factors which were identified were all related to the core category, 'Being in control', which was a key concept also noted within this case study and discussed in detail within the previous section. The first factor was 'knowledge' and this was closely connected to the core 'control' category with the level of knowledge an individual had in relation to their feeling of being in control. This was not observed within this particular case study as some participants who demonstrated a strong desire to be in control often had knowledge gaps and, more importantly, did not seek to know any more about the condition as this may have challenged how they maintained control. Therefore, the situation is more complex than Murphy et al.'s explanation.

It has been noted that little exploration has been undertaken to date around the patient experience in relation to education and support for managing diabetes and how this influences how the individual self-manages their diabetes. Crowe et al. (2016) have explored such experiences in patients with type 2 diabetes with sub-optimal glycemic control in New Zealand. A significant finding from this study was that the majority of participants had been given limited helpful self-management support. Synonymous with the findings of this thesis, it appears that the lack of patient-centred approach to supporting self-management has also been noted in other countries, thereby emphasising that a patient-centred approach to supporting self-management is clearly not as simple and straightforward as previously assumed.

The second factor raised by these authors was support from family, peers and HCPs. This was noted also to be an essential consideration within this case study and in particular the awareness that some may not be able to identify any support people within their lives, for example, Charles and Peter. This needs to be a consideration when undertaking patient assessment. The third factor was motivation, with levels of motivation being related to self-management

practices. Motivation was assessed using a motivation scale in the participants of this case study and, although most rated self-monitoring highly in terms of importance, the majority scored lower for confidence, therefore confidence-building is of high importance when developing self-management interventions. The fourth factor was relationship shift, one that addressed the changing relationship between patient and HCP once knowledge and understanding was gained, hence moving from a paternalistic model to one of patient power to collaborate, which was a key issue affecting patient engagement in this case study. The fifth factor was empowerment, again a key theme within this case study, which has been discussed in detail. Murphy et al. (2011) related empowerment to the building of control to gain power. Authors note that it is the understanding of these factors which has the potential to allow HCPs to provide more focused and empowering diabetes care and management and also note that by exploring patient experience and expertise we can assist patients to develop their 'internal resources', thus improving engagement with their self-management (Murphy et al. 2011).

In addition to patient understanding of self-monitoring and applied self-management being poor, this case study demonstrated that understanding of risks associated with poor control does not always influence actions and problem solving. Tam, Brian and Michelle all understood in theory the risks associated with poor control yet all consistently maintained unstable and higher than recommended glycemic levels. Furthermore, there was an identified need for better understanding around diabetes for other groups: relatives, support people and health care staff for whom diabetes is not their main remit. It was noted that health care staff may be embarrassed and feel that there is an expectation for them to be expert in all conditions and because of this may avoid seeking clarification on management of diabetes. This study identified that although there are educational programmes around diabetes and self-care available for patients, there is limited information or opportunities available to support people.

Limited understanding around diabetes can have serious consequences for healthcare situations, including: poor/dangerous care which is not patient-

centered; and reduced public confidence, where patients and support people are left feeling frustrated, concerned and lacking confidence in health services. A Swedish study evaluated knowledge and understanding around diabetes in nursing home care staff. Staff were asked to read a diabetes case and reflect on their knowledge regarding diabetes within the case and diabetes in general. The level of knowledge among the participant health workers varied. Some were able to identify that the individual referred to in the case was suffering from hypoglycaemia but there was minimal linking of the symptoms described in the case to this. Authors conclude that basic and ongoing education should be provided to health care workers who care for patients with diabetes and a call for future research to explore possible interventions to provide this (Smide and Nygren 2013). This study also identified a need to update patients and support people. This case study's findings also supported this need to update and raise awareness of the needs of diabetes self-care for HCPs for whom diabetes is not their main remit.

It is not just the theoretical and clinical care knowledge that is important for HCPs to understand. It has been noted that nurses who are responsible for facilitating diabetes education in health care may not have the required insight into the psychosocial factors that influence diabetes to effectively support patients in their self-management (Smith-Miller and Thompson 2013). With this in mind, training and up-skilling for practitioners who are facilitating this type of education needs to cover more than just the theory content but should also take into account educating the educator in the associated sociological perspectives. It appeared from this case study that some of the participants had very key goals which drove their self-monitoring and self-management behaviours, for example, golfing and regular visits to the pub. Perhaps working more closely with patients to explore patient-centered goals can foster a more engaging relationship between HCP and patient.

HCPs referred to the difficulty in getting patients to fully understand the importance of good glycemic control in terms of reducing risks. Expanding this further, Podiatrist Colin talks about how there is a disconnect between understanding risks and applying this to how patients manage their condition.

Shock tactics have been used in recent years to get the message across to patients regarding public health issues. This approach has demonstrated good outcomes in terms of public engagement; for example, the use of graphic images on cigarette packaging, which triggered a significant increase in calls to smoking cessation services (Miller et al. 2009). However, there have been concerns raised regarding such public health interventions with calls to consider ethical considerations and explore more positive appeals (Guttman and Salmon 2004; Lewis et al. 2007). This approach appeared to be effective in Brian's case, when he describes being shown patients affected by diabetes-related complications. The use of fear in social marketing is a highly debated topic as, although such tactics can have impact, care must be taken to ensure that messages reach the intended target group, disseminate the desired message and do not cause undue anxiety (Parry et al. 2013; Sherr 1990). As there was a noted need for more risk awareness, and as this was a key motive for those demonstrating more long-term thinking, this is an area for future exploration, perhaps considering the use of regular reminders about risks with the aim of influencing longer-term thinking and analysis.

This lack of understanding may be the reason why large numbers of patients with diabetes are not meeting health targets in relation to their ability to self-manage good glycemic control (Calvert et al. 2009). This raises debate as to whether this is down to poor understanding or the individual not caring enough. An Australian qualitative study interviewed patients to explore this concept in more depth. Findings suggest that people do have a good understanding of their condition and its implications but they sometimes do not make diabetes a priority in their lives. This may be due to individuals choosing not to make the lifestyle changes required to facilitate good glycemic control and how associated life and social factors can affect this, for example, Brian's priority was to continue engaging in his social activity of going to the pub to meet with peers. Authors from the Australian study therefore concluded that poor control is not related to lack of knowledge and understanding (Greenfield et al. 2011).

Barriers to ensuring good understanding around diabetes should also be considered. Resource, time and access are all important factors when

considering how to improve patients' health literacy, problem solving and self-management in relation to diabetes as well as training for those involved in educating patients (Khazrai et al. 2015).

Assessing patients' understanding of SMBG and its application can be a difficult process. As noted in this case study it can be those who appear to fully understand, for example Maureen, who had worked in diabetes care, and Charles, a well-educated University lecturer, who in fact were not fully informed regarding the importance, the process and the application of SMBG, although Charles in particular used particular strategies to make it difficult for HCPs to determine his lack of knowledge of self-management.

In summary, evidence has indicated that very few people are partaking in diabetes education programmes. Patient knowledge and understanding relating to SMBG, how to undertake the process, how to apply the findings and its importance, are imperative to allow patients to effectively self-manage their condition and reduce the risk of complications. This knowledge and understanding needs to move beyond 'the process' to allow patients to problem solve and critically analyse results. Motivation, empowerment and self-efficacy are all important in the process of patients effectively self-managing their diabetes, with an overall aim of being 'in control'. As education in relation to SMBG is not accessible to all and sometimes not to those who most need it, or encouraged to those who may present as knowledgeable, there is a need to identify those patients who fall through the gaps in the progression of diagnosis and the building of knowledge and understanding pathway of diabetes care. More importantly, there is something not working with diabetes self-management education as people with high levels of education are not able to take it on board and act on it.

In addition to facilitating patients to acquire all of the necessary skills, there needs to be a consideration of psychosocial factors and education, up-skilling, and refreshing, which should not be limited to the patient themselves but should also include support people and health care staff, for whom diabetes is not their main remit. HCP training is important in raising awareness regarding the dangers of ignoring diabetes in terms of the need for hospitalisation and

medical emergency. In addition, systems within secondary care need to acknowledge the need for specialist advice when patients with diabetes are admitted to hospital and explore how this can be facilitated.

7.6 Fear of low blood glucose/hypoglycemic episode connected to maintaining blood glucose levels above recommended levels

Some of the participants in this case study, and particularly those who demonstrated more limited problem solving abilities, were noted to maintain blood glucose levels higher than the recommended limits and the underpinning rationale for this appeared to be due to fear of hypoglycemic episode. This fear was generated by the unpleasant physical feelings associated with hypoglycemic episodes along with the potential medical emergency situation which hypoglycemia can lead to. It is recognised that the feelings associated with hypoglycemic episodes can evoke fear and anxiety in patients with diabetes and this fear can influence how patients manage their diabetes, inhibiting effective self-management. In addition, this fear can also affect emotional health and quality of life (Martyn-Nemeth et al. 2016; Wild et al. 2007).

A Canadian study assessed the impact of hypoglycaemia and the fear of hypoglycaemic episodes on type 1 and insulin-treated type 2 patients. Findings from this study identify that more type 1 patients reported increased fear following a hypoglycemic episode than type 2 patients. Also, the most common response to fear of a hypo was self-treatment, for example, lifestyle and self-management modification to avoid further hypoglycemic episodes in the future (Leiter et al. 2005). This research did not refer to patients maintaining blood glucose levels above recommended limits, although it should be noted that the study used a patient self-reported questionnaire and patients may be reluctant to admit to managing their blood glucose in this way. In fact, those who maintained blood glucose levels higher than recommended within this case study were unaware of doing this and therefore if they had been questioned specifically about this behaviour they would be unlikely to report that they managed their diabetes in this way. This type of behaviour requires deeper exploration.

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Those participants in this case study noted to undertake this behaviour also reported feeling less confident about dealing with higher blood glucose levels than lower levels, for example, Tam, Michelle and Angus. Therefore, in addition to an underlying fear of the physical effects and medical emergency of a hypoglycemic episode, there may also be the underlying lack of understanding regarding how to deal with higher blood glucose levels which results in these individuals taking no actions when blood glucose levels reach levels which are too high.

A review of the literature identified that although 'fear of hypoglycemia' (FOH), is a recognised phenomenon, there is very little research in this area. Results of this review suggest that FOH is not uncommon and is connected to previous experience of hypoglycemia and those who experience extreme variations in blood glycose levels. Evidence from this review also suggests that this fear can have a negative impact on diabetes management, metabolic control and, in turn, health outcomes (Wild et al. 2007). A more recent review by Martyn-Nemeth et al. (2016), examining current approaches and gaps, noted that FOH is connected to age and gender, with women experiencing FOH more frequently than men, the relationship with age categories was more complex, and FOH was also connected with duration of living with diabetes. Fear was noted to be greater in the evening, thus affecting sleep patterns and, in turn, quality of life. FOH was related to social situations and was related to embarrassment of being seen to lose control, but was also related to isolation; fear of being alone and needing assistance (Martyn-Nemeth et al. 2016).

More research is required to determine how fear of hypoglycemic episodes develop and the type of characteristics that may make individuals more likely to suffer from this fear. Diabetes education programmes need to address FOH and raise awareness of blood glucose levels. Psychological interventions, such as cognitive behavioural therapy (CBT), have been shown to be effective in dealing with this type of fear (Martyn-Nemeth et al. 2016). However, it should be noted that CBT tends to deal with negative and unrealistic thoughts (Benson 2007), but, for many patients, FOH can be a rational fear backed up by experience and therefore other types of interventions are needed. Research

needs to explore interventions which will decrease fear of hypoglycemia in those most vulnerable, in conjunction with encouraging stable blood glucose control (Wild et al. 2007).

In summary, participants in this case study were noted to self-manage blood glucose to allow them to maintain their blood glucose levels at higher than recommended levels. This appeared to be due to a fear of hypoglycemic episode due to the physical effects associated with this and prospect of medical emergency but also because of lack of understanding in terms of managing upper levels. Experiences of severe hypos are immediately affective and people react to and try to prevent these very real, unpleasant and dangerous situations. Paradoxically, in addressing the possibility of this immediate danger, they actually increase their chances of experiencing the adverse consequences of maintain high blood glucose in the future.

'Fear of hypoglycemia', is a recognised concept which was mentioned specifically by several participants within this case study and has been considered and reviewed in the literature. However, little is known about those who experience this fear and how we can address this fear in practice.

7.7 Study Strengths and Weaknesses

The study utilsed a two-stage process. Firstly a scoping study was undertaken to describe the extent of the problem which was then followed by a large qualitative study. A criticism for this approach can be determining where the priority and focus lie. In addition it may not be clear how each part connects and informs the other.

The study sought to overcome these criticisms by taking a methodical, progressive and logical approach; by first identifying the issues in relation to self-monitoring through evaluation of the literature and then assessing the extent of the problem in the statistical analysis. As there was an identified need for deeper exploration of why patients are not undertaking this process as recommended, the natural next step was then to undertake exploratory work in the form of a case study. It was determined and is made clear within this thesis

that the end point qualitative case studies were prioritised in terms of answering the core research questions.

As the focus of this study was qualitative, the main potential criticism is the absence of scientific rigour. Rigour was enhanced in this part of the study by utilising multiple data collection methods, otherwise known as triangulation, therefore taking more than one viewpoint. The multiple methods used, including semi-structured face-to-face interviews, patient diaries and phone interviews, provided a variety of accounts of how patients self-monitor, how they apply their results, and the many factors affecting this process. The additional data generated through HCP and support person interviews were used to assist with gaining insights into all the dimensions of the processes of SMBG. This method, as Yin (1999) argues, is highly complementary as each source can be compared with others (Yin 1999). In addition to the varying types of data, these data were collected at differing time intervals and separately. For example, interviews with support people and HCP were undertaken at a different times and in the absence of the participant. This allowed support people to be honest regarding their views, which generally affirmed the participants' points but occasionally contradicted them. This was significant during the analysis stage.

The credibility and reliability of the analysis was undertaken through a data testing process. This was undertaken by presenting data for interpretation to an HCP; diaries were given to a diabetes consultant for additional interpretation and the initial results of the analysis were presented at a diabetes team meeting (including medical staff, nursing staff and a podiatrist) to seek their feedback. Academic supervisors also read transcripts which were subsequently discussed during supervision team meetings.

There were some concerns that some participants displayed strong characteristics within the data that were collected which may make them identifiable. This was also checked with the diabetes team when the initial findings were presented at diabetes team meeting. The team felt that they could not identify their patients from these findings but noted that the data presented represented many of their patients, one diabetes consultant

commenting, "We have lots of Paulines". Therefore as well as confirming that ethics were not compromised through patient identification it also confirmed that the sample was capturing different types of patient.

The patient diaries provided a picture of what the patient is actually doing, how this affected the results and how are they then problem solved with regards to the result and actions. Using diaries to collect data offers further depth about behaviour lifestyle patterns and self-management, and offers an adjunct to interviewing in qualitative research. It has been suggested that diaries are a more accurate method than obtaining data through recall during interview, with a noted high reporting level which effectively captures the individual's perceptions of situations (Burns and Grove 2005; Moule and Goodman 2009). The reason for this is that diaries allow an individual to report and contemplate on situations, at the time of or very shortly after a situation, thereby reducing errors in recall. Also, participants may feel more comfortable to discuss thoughts, feelings and influences, something that they may feel less at ease with in the company of an interviewer (Moule and Goodman 2009; Nicoll 2010). However, in this study, the diaries' contents are limited to a particular snapshot of time and therefore are unable to capture and explore multiple issues, and it is for this reason that the participant diary has been used in conjunction with other methods of data collection (Alaszewski 2006). The length of time needed to perform diary recording was carefully considered, as it can affect recruitment and response (Nicoll 2010). This was done through the completion of pilot diaries prior to recruitment. The diaries provided illuminating results with additional insights, which included Brian's response to extremely high blood glucose results and his desire to continue his lifestyle habits. In addition, Angus' frustration with fluctuating results was evident in his diary. These points did not arise during the interviews.

Rigour was also applied to the qualitative part of this case study by using a structured approach to the analysis of the data which was underpinned by a theoretical model. Analysis was completed through the use of a constant comparative method (CCM), first described by Glaser and Strauss (1967). This approach in is often linked to use alongside Grounded Theory, but there is

strong justification for the strengths of this approach in any study where inductive exploration is required, which utilises theoretical underpinning, then allowing deduction (Fram 2013). As data were coded into categories, these categories were mapped and organised around the theoretical framework, thus allowing visualisation of the data through the lens of the key concepts of this theoretical framework. All data were then systematically and continually compared to all elements of other data in the dataset. This allows for the emergence of themes which unrestrictedly capture the essences of the data (Glaser and Strauss 1967) and also allows for unanticipated themes to be systematically identified (Thomas 2011).

The approach requires the researcher to be very well acquainted with and fully immersed in the data. The researcher interviewed all the participants and transcribed all of the interview data herself, as well as the diary extracts, which provided this close familiarity with the data (Miles and Huberman 1984).

The creation of the conceptual model based on Stones' structuration theory enhanced the researcher's ability to be unrestrictive regarding the number of themes emerging from the data. In addition, the model provided an outline structure on which the researcher could map the themes and conceptualise how each of these areas feed into each other.

As noted in the methods section (5.5), the researcher's background experience and skills were important and influential in the recruitment and engagement with participants during the fieldwork process. This provided a definite strength to the study through engagement with the participants and health services, enabling recruitment and the underpinning understanding for the interviewing process.

Although this was a relatively small sample of cases, in a qualitative case study there is no precise sample size, although some authors have suggested that there should be around four to five cases. The convenience approach to sampling may also been seen as a weakness, although the varied mix of demographics within this case study partly belies this, for example, the mix of sex, age ranges, type of diabetes and length of diagnosis. In fact, the sample

variation was noted to be one of the strengths of this study, in particular the varied levels of education, which emphasised the difficulties that people from all education backgrounds can have with self-managing diabetes. A method of overcoming small sample size in this type of research is to continue recruitment until saturation is noted (as described in the sampling section in section 5.2.3. In this case study, saturation was noted after case nine and therefore one further case was recruited as, in addition to saturation, a varied population mix was noted. In addition to overcoming the issue of small sample size, supporting data were obtained from patient diaries and HCP/Support people interviews.

The low response by HCPs and support persons in the recruitment process did not allow for the full complement of supporting evidence, which was a noted weakness within the study. In addition to this, not all participants returned the patient diary. The addition of this supporting evidence may have identified other factors relevant to this study. There was a limited response rate from certain HCP disciplines; there were few responses from General Practice. The researcher did attempt to follow these up with HCPs through the patient participants but ethical concerns precluded the researcher from contacting the HCPs personally. However, this proved to be unsuccessful with all but one of the HCPs. Additional recruitment strategies need to be considered for future research design to ensure that all discipline perspectives are obtained.

Despite these limitations this study has taken a methodical and progressive approach whereby evidence has been gathered including statistical information as well as descriptive, the latter being underpinned by theory. Participation, response and sample size for the case study have been carefully considered and additional methods of integrating evidence have been used. This has allowed breadth and depth to the exploration, facilitating the emergence of key points and thereafter conclusions to be drawn.

CHAPTER 8: CONCLUSION

This study sought to consider self-monitoring of blood glucose in the wider context of diabetes self-management through a quantitative scoping study followed by a larger qualitative study approach. An initial review of the literature identified that, although self-monitoring of blood glucose has an important part to play in maintaining blood glucose levels close to normal with a view to reducing the risk of long-term complications, patients are not undertaking this process and relating it to their diabetes self-management as they should be and as recommended. Exploratory literature determined that many factors; individual, contextual and societal, may have a role to play in how patients self-monitor their blood glucose and then in turn use this information in the management of their diabetes. It has yet to be determined how the factors relate to the role that self-monitoring of blood glucose plays in influencing good health outcomes in diabetes and how we may be able to intervene in influencing such outcomes.

The next stage in this research was to identify the extent of the problem; how many of those who are recommended to test are testing often, how frequently, and whether there are differences between population groups. This was achieved through statistical analysis. The outcome of this work supported the literature in reporting that, of those individuals with diabetes who are recommended to test, many are not testing at all, and of those who are testing, a large proportion are not testing as frequently as recommended.

Based on the literature review and statistical data analysis, there was a clear need to explore self-monitoring of blood glucose and its application to self-management from an individual point of view and in the context of their world, thereby guiding the qualitative phase of this study. Analysis of the case study results identified six key motives for self-monitoring blood glucose, the associated responses and behaviours relative to this motive and the underpinning attitudes and beliefs. The connections between the responses to these motives and the underpinning attitudes and beliefs were mapped to

demonstrate the complexity of linkages between what happens and why within each individual.

Five key discussion points emerged from the analysis. The differing relations were noted between individuals and their diabetes and how this was linked to the level of engagement they had with their condition. There is the feeling that it is the people who want to improve their control who will test, suggesting that those who do not test either feel they cannot improve the control or do not want to make the necessary changes to improve. This emphasised the importance of motivation which was strongly associated with the individual's level of engagement with their condition and how this built self-efficacy and empowered them.

The second discussion point was that of resistance, which was noted in some individuals towards health services as well as their support people. There is a need to re-engage those who have developed resistance over time to build their self-efficacy and empower them. Health structures need to alter to facilitate this change, and move away from the rigidity and red tape that was noted in this study to cause frustration in HCPs who were unable to apply technical processes to analyse blood glucose results or use technology for education.

Experience was also an important factor in this this process of self-monitoring of blood glucose, for example, past experiences in relation to living with their condition. Resentment in relation to past experience was noted in some, which again significantly affected their engagement. Measures to reduce these frustrations, which affect the positivity of reviews, may alleviate these feelings, for example: limit waiting times during clinic visits; personalise care; and provide more continuity of care where possible. Perhaps more communication but less waiting may mean that assessments are made online without face-to-face contact for some checks. Clinicians noted that email worked well in relation to communicating with patients who were too busy to attend regularly, therefore, through individual assessment approaches, perhaps there could be a mix of face-to-face and email communication for those suited to this type of process. This would free up more face-to-face time with clinicians and reduce

anxiety and frustration around waiting times for what is deemed a 'tick-box' process.

Consideration of the above may encourage more trust between patient and HCP and help us move from the situations where patients are pretending to conform and changing behaviours around review times to allow them to present results that are not in keeping with their actual blood glucose control; a situation which, ironically, HCPs are fully aware is happening.

Both patients and HCPs recognised that, actually, when patients do pay attention to self-monitoring, improvements were noted in blood glucose control. The problem is sustaining this attention to testing. Frustration due to lack of understanding was a noted barrier to sustaining this attention. There was a clear need to address patient understanding around self-monitoring and applying this to self-management. Although education is available, it is those most at need who are not accessing this. These are the individuals who need to be targeted in terms of educating and up-skilling, as well as those who have 'fallen through the gaps'; those for whom there is assumed knowledge and understanding (HCPs and the well-educated). Thorough assessment of patient understanding around diabetes self-care and assistance with practical application, problem solving and longer-term thinking and analysis will help to identify those most at need. Education priorities should be: the dangers of high blood glucose (short-term and long-term) and the link between poor glycemic control and diabetes-related complications.

Evaluation of educational initiatives around the use of regular updates or reminders in relation to diabetes and self-management will identify what works and for whom. This should include not only patients but also healthcare staff who are not working with diabetes regularly.

8.1 The Model

Stones' version of structuration theory was able to consider all aspects of the study aims. It was used to provide a framework for the organisation of the study findings and analysis. Exploration of application of this theoretical model identified that many studies have used structuration theory; some have used an

adapted version or have used it in combination with another theory to explore human health behaviours (Beringer et al. 2006; Chan et al. 2010; Greenhalgh et al. 2013; Hardcastle et al. 2005; Kairy et al. 2014; Lehoux et al. 2002; Leydesdorff 2010; Turgeon et al. 2006; Ulucanlar et al. 2013; Wheeler et al. 2014). Over the last decade, several health-related studies have used Stones' version of structuration theory to theoretically synthesise research. For example, Hinder and Greenhalgh (2012) sought to obtain a deeper understanding of the lived experience of the self-management of diabetes by using this theory. Their study noted the demands of self-management on the individual (physically, emotionally and socially) and how this linked to engagement and resilience in the context of personal, family and social circumstance. The authors recommended further research to explore in more detail the challenges around living with diabetes (Hinder and Greenhalgh 2012). Utilisation of the model in this study allowed in depth exploration of factors affecting real life which was an important factor within this study and assisted in the identification of the differing relationships individuals have with their condition and how this in turn then affected their engagement with their condition.

Another of Greenhalgh et al.'s (2013) studies applied this theory when exploring what matters to older people with assisted living needs in a telehealth and telecare research study. The authors noted that the needs of the study population were diverse and unique, hence they required a tailored approach rather than standardised approaches, which are often synonymous with telehealth and telecare. The researchers therefore drew upon the contextual nature of structuration theory within the study design to allow for the exploration of wider aspects and views (Greenhalgh et al. 2013). It was noted that the model allowed consideration of complex needs within a population, which is not dissimilar to considering the needs of those managing a chronic illness. Here the model assisted in linking these complexities with educational needs, noting gaps in knowledge and the link between complexity and individualized focus.

Greenhalgh et al. (2014) again used this version of the theory to explore the implementation of an outpatient booking system and to study the relationship

between the external environment, the new technology and actions of the human agents, namely, the GPs, administrative staff and patients. The framework was used to allow the separation of structure and agency and macro, meso and micro structures. It was noted that technology is a concept missing from the original analytical framework of structuration theory. As the overall management of diabetes occurs within health structures and processes and then requires the individual to self-manage within outer structures, both of which may include technology, these were necessary factors which needed to be incorporated to the theoretical thinking within this study. The model allowed the consideration of the importance and influences of diabetes reviews and how this can influence engagement and associated self-management behavoiurs.

The model's four broad themes allowed for full exploration of all factors without constraint and also allowed for the identification of other significant factors not fully addressed with the model.

Giddens applied the notion that discrepancies or variations in views or data should be seen as facilitators to uncovering topics, as opposed to a weakness (Giddens 1984). This was particularly relevant in this study, as what patients said and what they did where often miles apart, and, more importantly, this gap is something that individuals appeared to have limited self-awareness of.

8.2 Implications for future practice and research

- As very few individuals with diabetes are attending education programmes, further research is needed to identify the reasons for this poor uptake; how are programmes being presented and marketed to patients? How can education be tailored to suit individual needs and improve uptake?
- Assessment of understanding in relation to self-monitoring of blood glucose and applying results to self-management, as well as the implications of poor self-management in terms of diabetes-related risks. This extended to those who support patients with diabetes as well as and HCPs who do not work directly in diabetes care. In relation to HCPs' understanding, research could explore the feasibility of providing

specialist advice in hospital areas at all times to ensure that patients with diabetes have all necessary care and equipment. Further research in this area could also assess confidence in relation to diabetes care and management and evaluating education initiatives.

- It was noted that many patients use the results of self-monitoring of blood glucose to manage their diabetes reactively and in the short term with limited long-term thinking and planning. Exploration and testing of longer-term diabetes management teaching will allow for the integration of long-term planning concepts into education programmes.

- Engagement was also an influential concept in this study. Future studies are required to assess engagement: studies to assess the effect of different educational and medical approaches depending on level of engagement, may assist in our understanding of how to approach those who are less engaged, thereby raising awareness that one size does not fit all.

- Continuing the theme of engagement, 'the supportive relationship' for patients when engaging with health services as well as those around them is something which can have an impact on how diabetes is self-managed. Patient engagement therefore needs to be considered and included in health service interventions relating to diabetes self-management. In particular, consideration of the language health professionals use when engaging with patients is important, for example, using terms such as 'scores' when discussing the results of self-monitoring may make patients feel as though they have failed and this will subsequently affect future engagement.

- One of the key discussion points within this study was fear of hypoglycemic episodes and how this influenced patients in maintaining blood glucose levels above those recommended. Review of the literature noted very little research in this field, particularly in relation to the behaviours in terms of maintaining blood glucose levels too high. More research could explore patient management and interventions to raise awareness of the dangers of this behaviour as well as HCP retraining to avoid this.

8.3 Competing interests

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APPENDICES

Appendix 1: Academic Publication

research letter

Patterns of self-monitoring of blood glucose in insulin-treated diabetes: analysis of a Scottish population over time

Analysis of a diabetes clinical information system in Tayside, Scotland, shows that a significant proportion of insulin-treated patients with diabetes are not self-monitoring blood glucose according to current clinical guidance and recommendations, with some not self-monitoring their blood glucose at all. Although there has been an increase in the number of reagent strips dispensed over the past decade, this increase is mainly accounted for by increased testing frequency among people with diabetes already testing.
Keywords: database research, population study, type 1 diabetes, type 2 diabetes

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Introduction

Self-monitoring of blood glucose (SMBG) is fundamental to diabetes self-management for people with type 1 diabetes and those with type 2 diabetes treated with insulin [1,2], and has an important role to play in the prevention of hypoglycaemia and in the reduction of longer-term complications. Current guidance recommends routine SMBG in type 1 diabetes at least four times per day and possibly even up to 10 times daily, with frequency and timing individualized to the patient [1–3]. Guidance for type 2 diabetes suggests that routine testing should be undertaken by people treated with insulin [1,4–6] and anyone at particular risk of hypoglycaemia.

Studies have shown a general increase in SMBG over the past two decades in the UK and elsewhere [7,8]. Frequency of testing has increased, alongside increases in the numbers of those testing. A study in Scotland identified an increase in the proportion of all people with type 2 diabetes carrying out any SMBG from 15.5% in 1993 to 29.8% in 2009 [7]; however, it is perhaps more important to assess the level of testing in patient groups for whom regular testing is specifically recommended. We therefore used a record-linkage diabetes clinical information system in Tayside, Scotland, to investigate patterns and levels of SMBG among people with type 1 diabetes and those with type 2 diabetes treated with insulin.

Methods

The Health Informatics Centre, University of Dundee [9,10] uses the record-linkage of healthcare data to facilitate epidemiological and health services research in Scotland. Record-linkage is enabled by the widespread use of a unique health care identifier (the CHI number) that is allocated to people when they register with a general practitioner in

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Scotland. The Scottish Care Information – Diabetes Collaboration (SCI-DC) is a validated population-based diabetes information system that has been compiled by record-linking several independent data sources [6]. Detailed clinical information is available via the SCI-DC for all people with diabetes. There are also computerized records of prescriptions dispensed, including those for self-monitoring equipment to residents of the region of Tayside (current estimated population is 412 160). These are free of charge so almost everyone with diabetes is likely to obtain their reagent strips via this route.

People in Tayside with either type 1 or type 2 diabetes, who were dispensed at least one prescription of insulin during that year were identified for the period 2004–2011. The total number of SMBG reagent strips dispensed to them was calculated from information on the prescription. A cross-sectional analysis of a 3-year period, 1 January 2009 to 31 December 2011, was also undertaken. We investigated whether SMBG patterns were associated with age, sex and a postcode measure of material deprivation that classified people into quintiles of deprivation (according to information on income, employment, health and disability, education, skills and training and access to services for small geographical areas) [6]. The proportions of people testing within sub-groups and the median number of strips dispensed in the 3-year period were also determined.

Results

The overall number of SMBG reagent strips dispensed has almost doubled over time, from 833 500 strips dispensed to 1225 people with type 1 diabetes in 2004, to 1 574 950 strips dispensed to 1573 people in 2011. Similarly, in type 2 diabetes, the number of SMBG strips dispensed increased from 950 400 dispensed to 1830 people treated with insulin in 2004 to 1 416 200 dispensed to 2473 people in 2011 (Table 1).

Table 1. Number of self-monitoring of blood glucose reagent strips dispensed by year and the number of patients with any strips dispensed.

	Type 1 diabetes				Type 2 diabetes			
Year	Patients, N	No. of strips dispensed	Patients with strips dispensed, n (%)	Median no. of strips dispensed per day*	Patients, N	No. of strips dispensed	Patients with strips dispensed, n (%)	Median no. of strips dispensed per day*
2004	1698	833 500	1225 (72)	1.4	2073	950 400	1830 (88)	1.1
2005	1712	882 250	1464 (85)	1.2	2128	1 096 300	1934 (91)	1.2
2006	1802	1 100 200	1376 (76)	1.6	2273	1 201 350	2065 (91)	1.2
2007	1845	536 000	1207 (65)	0.8	2228	1 018 100	1952 (88)	1.1
2008	1882	648 450	1179 (64)	1.0	2246	1 006 555	1959 (87)	1.1
2009	1951	810 900	1337 (68)	0.5	2466	1 236 950	2176 (88)	1.2
2010	1946	1 432 100	1554 (80)	1.9	2597	1 352 100	2337 (90)	1.2
2011	1969	1 574 950	1573 (80)	2.2	2718	1 416 200	2473 (91)	1.4

*Among patients with any strips dispensed.

Table 2. Numbers of self-monitoring of blood glucose reagent strips dispensed and numbers of patients receiving strips, stratified by gender, age and deprivation level.

	Type 1 diabetes			Type 2 diabetes		
Attribute	N	Patients with strips dispensed, n %)	Median no. of strips dispensed per day*	N	No. (%) of patients with strips dispensed	Median no. of strips dispensed per day*
Gender						
Female	818	738 (90)	1.8	941	872 (93)	1.0
Male	982	845 (86)	1.4	1053	950 (90)	1.1
Age						
13–24 years	408	362 (89)	1.4	4	4 (100)	0.3
25–40 years	539	451 (84)	1.1	70	56 (80)	0.5
41–55 years	545	483 (89)	1.6	377	338 (90)	0.7
56–70 years	233	218 (94)	2.1	848	789 (93)	1.0
≥70 years	75	69 (92)	2.4	694	534 (77)	1.4
	1800					
Deprivation quintile						
1 (most deprived)	324	287 (89)	1.2	448	412 (92)	0.9
2	364	312 (86)	1.3	426	392 (92)	0.9
3	342	308 (90)	1.7	394	357 (91)	1.2
4	389	334 (86)	1.8	373	341 (91)	1.0
5 (least deprived)	312	284 (91)	1.9	307	292 (92)	1.2
Total	1800	1583 (88)	—	—	—	—

*Among patients with any strips dispensed.

The proportion of people with type 1 diabetes who received any strips increased from 72% in 2004 to 80% in 2011, suggesting that there are still around one in five of patients who are not testing at all. The approximate doubling in the number of strips dispensed over time can be attributed almost equally to increased numbers of people testing, and to increased frequency among those already testing (as shown by an increase in the median daily number of strips dispensed). In contrast, in type 2 diabetes, the proportion who test has remained relatively stable over the study period; 88% in 2004 and 91% in 2011. The large increase in the overall number of strips dispensed is therefore accounted for by increases in testing frequency among those who already test, rather than being an indication of wider engagement with SMBG. Despite this, many people are still not receiving enough strips to test more than once or twice daily.

Table 2 shows that between 2009 and 2011, women are more likely to test, and people with type 1 diabetes are testing more frequently. There was an effect of deprivation on frequency of testing, with people living in less deprived areas testing more frequently than those living in more deprived areas. In general, testing frequency increased with age but the proportion of older people (70+ years) doing any testing with type 2 diabetes was particularly low.

Conclusions

Despite a body of evidence identifying the importance of SMBG in maintaining glycaemic control and in turn decreasing the risk of diabetes-related complications [6,10], around 10–20% with type 1 and type 2 diabetes who are treated with insulin

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are not testing at all. This level of non-testing has remained stable over the last decade. Furthermore, testing is not carried out as frequently as recommended within both patient groups. These low levels of testing are worrying given the importance of SMBG in the prevention of hypoglycaemia, and its possible implications for behaviours such as driving. There is also evidence that SMBG may be associated with reductions in diabetes-related complications. These findings therefore have significant implications for health costs for individual people and health services [10–12].

The effect of deprivation on frequency of testing has been noted by several authors, in particular in type 2 diabetes, and is a concern given its potential to widen inequalities in diabetes outcomes [7,13–16]. It is important that everyone who is treated with insulin and for whom SMBG may be beneficial has appropriate knowledge about testing recommendations and the practice of self-monitoring [16].

The strengths of the present study are its population-based approach and the use of a validated diabetes clinical information system, with records of *dispensed* prescriptions for reagent strips; however, we cannot be sure that people necessarily used the reagent strips that were dispensed to them, and neither can we be sure that some did not receive strips from other sources. The study does identify a need for a deeper understanding of why people are not self-monitoring in line with current guidance. There is also a need to investigate further how people are testing as well as influences on testing behaviours.

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Acknowledgements

Conflict of Interest

The authors do not declare any conflict of interest relevant to this manuscript.

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Appendix 2: Consent Forms

2.1 Patient Consent to Contact Form

UNIVERSITY OF STIRLING

Self-monitoring of blood glucose study

PATIENT CONSENT TO CONTACT FORM

Please complete this form if you consent to speaking with a researcher regarding your potential participation in a diabetes study

		PLEASE INITIAL BOX IF YOU AGREE
1.	I understand that this consent is to speak with the researcher regarding the study and I will then have the option of whether to participate or not participate in the study	
3.	I understand that my consent to speak to the researcher or consent to participate in the study will not affect any future care and treatment.	
5.	I agree to have contact with the researcher	

_____

Name of participant

_____   _____

Signature   Date

_____

Name of witness (Consultant)

_____   _____

Signature   Date

Preferred method of contact

Mobile phone: _____

Telephone: _____

Email address: _____

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2.2 Patient Consent Form

UNIVERSITY OF STIRLING

Self-monitoring of blood glucose study
PATIENT CONSENT FORM

		PLEASE INITIAL BOX IF YOU AGREE
1.	I confirm that I have read and understand the information sheet (insert version and date) for this study and 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 from all parts of this study, including audio recording of interviews, without giving any reason and with no detriment to my care.	
3.	I understand that the research team will hold the information I give confidentially and my name will not be mentioned in any reports.	
4.	I understand that all information from this study will be kept in a locked filing cabinet at the University of Stirling and stored in a password protected folder.	
5.	I agree to participate in this study.	
6.	I agree to the interview being audio recorded.	
7.	I would like to be provided with the results of the study and agree for my preferred contact details to be stored until results are available	
8.	I agree to the researcher interviewing my identified 'health care practitioner' and 'support person', regarding my blood glucose self-monitoring.	

_____

Name of participant

_____   _____

Signature   Date

_____

Name of witness (Researcher)

_____   _____

Signature   Date

_____

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2.3 HCP and Support Person Consent to Contact Form

Appendix 8
HCP, Support consent form protocol 002 version 2 08/10/2013

HCP & SUPPORT PERSON CONSENT TO CONTACT

Please complete this section if you agree to participate in this study, to allow the researcher to contact you

		PLEASE INITIAL BOX IF YOU AGREE
1.	I understand that this consent is to allow the researcher to contact me regarding my participation in this study	
2.	I agree to allow the researcher to contact me to make arrangements to participate in this study	

Name of participant

Signature   Date

Contact details

Home telephone number

Mobile phone number

2.4 HCP and Support Person Consent Forms

UNIVERSITY OF STIRLING

Self-monitoring of blood glucose study

HCP & SUPPORT PERSON CONSENT FORM

		PLEASE INITIAL BOX IF YOU AGREE
1.	I confirm that I have read and understand the information sheet (insert version and date) for this study and 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.	
3.	I understand that the research team will hold the information I give confidentially and my name will not be mentioned in any reports.	
4.	I understand that all information from this study will be kept in a locked filing cabinet at the University of Stirling and stored in a password protected folder	
5.	I agree to participate in this study	
6.	I agree to the interview being audio recorded	
7.	I would like to be provided with the results of the study and agree for my preferred contact details to be stored until results are available	

_____

Name of participant

_____

Signature   Date

_____

Preferred contact details for the provision of study results (if you agree with point 7).

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Appendix 3: Information Sheets

3.1 Patient Information Sheet

UNIVERSITY OF
STIRLING

Self-monitoring of blood glucose study

PARTICIPANT INFORMATION SHEET –

Study Title: Exploring the application of self-monitoring of blood glucose results in insulin treated diabetes

My name is Dawn Cameron and I have worked as a Community Nurse and Practice Nurse for many years, assisting in the management of diabetes. My interest in this area has led me to undertake this research as part of a PhD at the University of Stirling.

You are invited to take part in this study, which explores the process of self-monitoring of blood glucose.

Before you decide if you want to take part, it is important for you to understand why the study is being undertaken and what it will involve. Please ask if there is anything that is not clear or that you would like more information on.

What is the purpose of the study?

Self-monitoring of blood glucose in diabetes self-management has been identified as important in assisting with the maintenance of normal blood glucose levels, which has the potential to reduce the risk of developing diabetic-related complications. However, we know very little about how people with diabetes carry out self-monitoring of blood glucose. In this study, we wish to explore how people with diabetes self-monitor in more detail by carrying out a number of in-depth interviews. We also hope to interview several health care workers and support persons. We hope that this will inform future education programmes for self-monitoring.

Why have I been chosen to participate?

You are being invited to take part in this study because you are a patient for whom routine self-monitoring of blood glucose may be recommended.

What will it involve?

If you are willing to be involved in this study, you will undertake a face-to-face interview with myself (Dawn Cameron). During the interview I will be asking questions regarding your self-monitoring of blood glucose practices and your views about self-monitoring and associated self-management. The interview will be audio recorded and will take approximately 45 minutes. It will be conducted in your own home or an office within the University of Stirling (travel costs to the University of Stirling will be provided). If interviews are undertaken in your own home, as part of health and safety requirements, my academic supervisor will be provided with the interview date, time and location. The interviews will subsequently be transcribed and anonymised, transcriptions will be stored securely and recordings will then be destroyed. Although anonymous quotes may be used in publications, you will not be identifiable in any way. However, there would be no detriment to future care should you wish to cease audio recording or participation in the study.

During the interview you will be asked to identify your key Health Care Practitioner. This will be the person who is most active in assisting you with your self-management and should be either your: Diabetic Consultant, GP, Clinic Nurse, Practice Nurse, Community Nurse or dietician

And your key

Support person: This will be the person within your personal life who supports you most in your diabetic self-management.

If you agree, I will then undertake a telephone interview with your identified key health care practitioner and support person. You will therefore be asked to provide these identified people with a 'consent to contact form', which can be returned to me in a prepaid envelope, allowing me to then make contact and undertake the telephone interviews. However, like yourself, they will be under no obligation to agree to take part if they do not wish to do so. This interview will focus on their perceptions and experiences around self-monitoring of blood glucose and you will be asked to consent to your self-management being discussed by your identified health care practitioner and support person.

The final part of your participation in this study will be completion of a patient diary over a 1 week period. You will be asked to select a normal/regular week (not including holidays or organised significant events) and at least two weeks after your last clinic visit. You should document in particular what influences you to self-monitor and how results influence your self-management, as well as your thoughts and feelings around this. The diary will contain detailed advice regarding completion and the researcher will discuss this with you following the interview and answer any questions you may have.

As a thank you for taking part in this study, you will be offered a £10 shopping voucher.

Do I have to take part in this study?
No. It is up to you to decide whether to take part. Participation in this study is entirely voluntary and you are free to refuse to take part or withdraw at any time without having to give a reason. This will not affect your care.

Please keep this information sheet for your reference. You will be asked to sign a consent form to confirm that you are willing to be involved in the study, which will be witnessed by myself. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

If your consent to participate in the study is declined or terminated at any stage, this will not affect your future care in any way.

Consenting will take place either within a University of Stirling office or at your own home.

Will my taking part be kept confidential?
You will not be named in any reports that we write about the study. The results of the study will be reported without mentioning names. All data, including your consent form and questionnaires, will be kept in a locked filing cabinet at the University of Stirling. Only

members of the research team will have access. In ten years' time all of these data will be destroyed.

What will happen to the results of the study?
Research papers will be published and study findings presented at conferences to disseminate the results to the wider research community. This will have the potential to inform future diabetic service planning.

Who will be supervising and funding the study?
The study will be run from the School of Nursing, Midwifery and Health based at the University of Stirling and will be under the supervision of Dr Josie Evans and Dr Leah Macaden who are experienced researchers within The University of Stirling.

This research is jointly funded by University of Stirling and 'LifeScan, Inverness'.

Who is reviewing the study?
All research in the NHS is looked at by an independent group called a 'Research Ethics Committee', to protect your interests. The East of Scotland Research Ethics Committee REC 2, which has responsibility for scrutinising all proposals for medical research in humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from the University of Stirling and NHS Forth Valley, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

What happens next?
If you are interested in taking part in this study I will contact you in a couple of days to confirm this and make arrangements for the interview. However you are also free to let me know then if you have changed your mind.

If you would like to further information regarding the study further or if you wish to discuss this with an independent contact, please find contact details below.

Researcher
Dawn Cameron
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3.2 Support Person Information Sheet

UNIVERSITY OF STIRLING

Self-monitoring of blood glucose study

PARTICIPANT INFORMATION SHEET FOR SUPPORT PERSONS

Study Title: Exploring the application of self-monitoring of blood glucose results in insulin treated diabetes

My name is Dawn Cameron and I have worked as a Community Nurse and Practice Nurse for many years, assisting in the management of diabetes. My interest in this area has led me to undertake this research as part of a PhD at the University of Stirling

You are invited to take part in this diabetes related study which explores the process of self-monitoring of blood glucose.

Before you decide if you want to take part, it is important for you to understand why the study is being undertaken and what it will involve. Please ask if there is anything that is not clear or that you would like more information on.

What is the purpose of the study?

Self-monitoring of blood glucose in diabetes self-management has been identified as important in assisting with the maintenance of normal blood glucose levels, which has the potential to reduce the risk of developing diabetic related complications. However, we know very little about how people with diabetes carry out self-monitoring of blood glucose. In this study, we wish to explore in more detail how people with diabetes self-monitor their blood glucose by carrying out a number of in-depth interviews with patients. We also hope to interview several health care workers and support persons. We hope that this will inform future education programmes for self-monitoring.

Why have I been chosen to participate?

You are being invited to take part in this study because you have been named as the support person for a person with diabetes for whom routine self-monitoring of blood glucose is recommended.

What will it involve?

If you are willing to be involved in this study you should complete the consent form which contains a 'consent to contact' section, and return this in the pre-paid envelope to me. I will then contact you to arrange a suitable time to undertake the telephone interview. The telephone interview will be undertaken by myself and will involve questions regarding your experiences of supporting a patient with diabetes in self-monitoring of their blood glucose, and also your views surrounding this. The interview will be recorded and will take approximately 30 minutes. The interviews will subsequently be transcribed and anonymised, transcriptions will be stored securely and the recordings will then be destroyed. Although Anonymous i quotes may be used in publications, you will not be identifiable in any way.

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However, there will be no detriment to you or the future care of the patient should you wish to cease recordings or participation in the study.

As a thank you for taking part in this study, you will be offered a £10 shopping voucher.

Do I have to take part?
No. It is up to you to decide whether to take part. Participation in this study is entirely voluntary and you are free to refuse to take part or withdraw at any time.

Please keep this information sheet for your reference. You will be asked to sign a consent form to confirm that you are willing to be involved in the study. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

The consent form is contained in this pack and should be completed and returned to myself..

Will my taking part be kept confidential?
You will not be named in any reports that we write about the study. The results of the study will be reported without mentioning names. All data, including your consent form and questionnaires, will be kept in a locked filing cabinet at the University of Stirling. Only members of the research team will have access. In ten years' time all of these data will be destroyed.

What will happen to the results of the study?
Research papers will be published and study findings presented at conferences to disseminate the results to the wider research community. This will have the potential to inform future diabetic service planning.

Who will be supervising and funding the study?
The study will be run from the School of Nursing, Midwifery and Health based at the University of Stirling and will be under the supervision of Dr Josie Evans and Dr Leah Macaden who are experienced researchers within the University of Stirling.

This research is jointly funded by the University of Stirling and 'LifeScan, Inverness'.

Who is reviewing the study?
All research in the NHS is looked at by an independent group called a 'Research Ethics Committee', to protect your interests. The East of Scotland Research Ethics Committee REC 2, which has responsibility for scrutinising all proposals for medical research in humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from the University of Stirling and NHS Forth Valley, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

What happens next?
If you are interested in taking part in this study when I receive your consent form I will contact you to make arrangements for the telephone interview. I will then telephone at your

preferred date and time to undertake the interview. However, should you change your mind regarding your participation you are free to withdraw at any time.

If you would like to further information regarding the study further or if you wish to discuss this with an independent contact, please find contact details below.

Researcher
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Independent contact
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School of Nursing, Midwifery and Health
University of Stirling
Stirling
FK9 4LA

Tel: 01786 46 6345
Email: William.lauder@stir.ac.uk

What if I wish to complain about the study?
If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through the University of Stirling, who are acting as the research sponsor. Details are available from the research team.

Thank you for taking the time to read this and to consider taking part in the study

UNIVERSITY OF STIRLING

Self-monitoring of blood glucose study
PARTICIPANT INFORMATION SHEET FOR HEALTH CARE PROFESSIONALS

Study Title: Exploring the application of self-monitoring of blood glucose results in insulin treated diabetes

My name is Dawn Cameron and I have worked as a Community Nurse and Practice Nurse for many years, assisting in the management of diabetes. My interest in this area has led me to undertake this research as part of a PhD at the University of Stirling.

You are invited to take part in this diabetes related study which explores the process of self-monitoring of blood glucose.

Before you decide if you want to take part, it is important for you to understand why the study is being undertaken and what it will involve. Please ask if there is anything that is not clear or you that would like more information on.

What is the purpose of the study?
Self-monitoring of blood glucose in diabetes self-management has been identified as important in assisting with the maintenance of normal blood glucose levels, which has the potential to reduce the risk of developing diabetic related complications. However, we know very little about how people with diabetes carry out self-monitoring of blood glucose. In this study, we wish to find out more about how people with diabetes self-monitor by carrying out a number of in-depth interviews. We hope to interview several health care workers and support persons. We hope that this will inform future education programmes of self-monitoring.

Why have I been chosen to participate?
You are being invited to take part in this study because you have been named as the Health Care Professional (Diabetic Consultant, GP, Practice Nurse, Clinic Nurse, Community Nurse or Dietician) supporting the self-monitoring of a patient with diabetes for whom routine self-monitoring of blood glucose is recommended.

What will it involve?
If you are willing to be involved in this study you should complete the consent form which contains a 'consent to contact' section, and return this in the pre-paid envelope to me. I will then contact you to arrange a suitable time to undertake the telephone interview. The telephone interview will be undertaken by myself and will involve questions regarding your experiences of supporting patients to self-monitor their blood glucose and your views about self-monitoring and associated self-management. The interview will be audio recorded and will take approximately 30 minutes. The interviews will subsequently be transcribed and anonymised, transcriptions will be stored securely and recordings will then be destroyed. Anonymousquotes may be used in publications. However, there will be no detriment to your

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patient's care or your position should you wish to cease audio recording or your participation in the study.

Do I have to take part?
No. It is up to you to decide whether to take part. Participation in this study is entirely voluntary and you are free to refuse to take part or withdraw at any time.

Please keep this information sheet for your reference. You will be asked to sign a consent form to confirm that you are willing to be involved in the study. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

The consent form is contained in this pack and should be completed and returned to myself.

Will my taking part be kept confidential?
You will not be named in any reports that we write about the study. The results of the study will be reported without mentioning names. All data, including your consent form and questionnaires, will be kept in a locked filing cabinet at the University of Stirling. Only members of the research team will have access. In ten years' time all of these data will be destroyed.

What will happen to the results of the study?
Research papers will be published and study findings presented at conferences to disseminate the results to the wider research community. This will have the potential to inform future diabetic service planning.

Who will be supervising and funding the study?
The study will be run from the School of Nursing, Midwifery and Health based at the University of Stirling and will be under the supervision of Dr Josie Evans and Dr Leah Macaden who are experienced researchers within the University of Stirling.

This research is jointly funded by University of Stirling and 'LifeScan, Inverness'.

Who is reviewing the study?
All research in the NHS is looked at by an independent group called a 'Research Ethics Committee', to protect your interests. The East of Scotland Research Ethics Committee REC 2, which has responsibility for scrutinising all proposals for medical research in humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from the University of Stirling and NHS Forth Valley, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

What happens next?
If you are interested in taking part in this study when I receive your consent form I will contact you to make arrangements for the telephone interview. I will then telephone at your preferred date and time to undertake the interview. However, should you change your mind regarding your participation you are free to withdraw at any time.

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If you would like to further information regarding the study further or if you wish to discuss this with an independent contact, **please** find contact details below.

Researcher
Dawn Cameron
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Tel: 07743147404
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Independent contact
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University of Stirling
Stirling
FK9 4LA

Tel: 01786 46 6345
Email: William.lauder@stir.ac.uk

What if I wish to complain about the study?
If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through the University of Stirling, who are acting as the research sponsor. Details are available from the research team.

Thank you for taking the time to read this and to consider taking part in the study

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Appendix 4: Interview Schedule – Patients

PATIENT INTERVIEW SCHEDULE

I would like you to talk as descriptively as possible, expand on all your idea (even if you think it is not related), ask me to clarify anything you don't understand and most importantly this is not a test I don't want to know how good you are at self-management, we want to understand what are some of the obstacles and difficulties so we can aim to improve things.

Can I start by asking how old you are and also at what age you where diagnosed with diabetes and commenced insulin therapy

How well do you understand your condition and associated self-management, in particular: SMBG

- What do you know about SMBG
  Why is it used in diabetes self-management?
  What does it do?
  What would happen if you didn't do it?
- How often should you SMBG?
  Who or what advised you of this?
  Do you do this in practice
- How important do you feel it is for you to self-monitor your blood glucose and can you rate this on a scale of 1 to 10, explaining why you have rated it at this level?
- What do you know about 'Goal Setting',
- *Explain that goal setting is a mutual and achievable agreement between the patient and Doctor regarding the level of blood glucose control to which the patient is aiming to achieve.*
  is this part of your self-management and is this done in conjunction with your Health Care Practitioner?
- What are the positive aspects of SMBG
- What are the negative aspects of SMBG

How do you undertake SMBG – Skill and Process

- What influences you to undertake testing?
  For example would they test prior to social events or hobbies and interests, would they test when the experience physical signs that alert them to test or do they test out of routine.
- How do you undertake the process; explain the steps you take when deciding to test, do you encounter any difficulties with undertaking the process and if so what are they?
- What kind of device do you have in terms of; does it store all the SMBG information?

How do you use results – Problem Solving Orientation

- Do you document your test results? How do you do this (electronically or written)
- If you document results, what do you do with them and do you share them with anyone?
- If you share them with anyone, how do you present the results to this person and how to they interpret or read the results?
- Following testing what actions do you take if any?
- What is your reasoning for undertaking these actions?
- How confident do you feel about problem solving with your results and can you rate it on a scale of 1 – 10?
- What do you feel influences this rating (for example what would push your rating higher)?
- Can you tell me what you know about recognising patterns and using patterns to manage your diabetes, do you use such methods and if so how do you feel this assists your self-management?
- Does anyone download your results and examine them for example in the form of a graph, if so can you explain this process.
- Can you tell me about the tools you use in self-management and do you use new technology in your testing and associated management, for example apps and web-based tools?
- What are your thoughts on the use of new technology in diabetes self-care in the future?

Past learning influences on SMBG Practices

- Can you tell me why we like to keep blood glucose levels above or below a certain level (probe to see if they will talk about risks)
- Can you tell me how you have learned about diabetes and how to manage your condition over time
- Can you tell me how this learning has influenced your practices
- Has any other learning influenced you management of diabetes (this can be non-health related)
- Have you attended or taken part in any diabetes learning programs, if so when and can you briefly describe the education program.
- Based on your experiences with diabetic related education or lack of, what are your thoughts around education programs in relation to SMBG?
- How has your participation in diabetic related education influenced your SMBG.

Appendix 5: Patient Diary

UNIVERSITY OF STIRLING

PATIENT DIARY

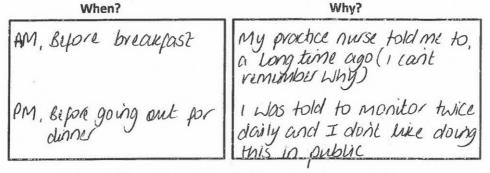## Instructions for Diary Completion

- Please complete this diary over a normal one week period (this should be a time which does not include holiday periods or organised significant social life events)
- On completion of the diary please return it in the pre-paid envelope to the researcher at your earliest convenience

Instructions for diary entries

- A descriptive diary entry should be completed at the end of each day

- The diary entry should be a reflection of your self-monitoring practices, thought processes and feelings over the day.

  1. The first part of the daily entry should contain a description of your self-monitoring; when you monitored, why you monitored and what influenced this. For example, it may be a routine time for you to self-monitor but also may have been influenced by another factor.

  2. The second part should describe what you did with the result; for example, did you document the result and if so was this in a diary or an on-line system. You can note your blood glucose result, if you can remember it or have documented it. However if you cannot remember your result, this is not a problem; this study is interested in your normal practices and thought processes and less interested in blood glucose levels. It is important that your behaviours and practices during the diary completion week reflect a normal week for you.

  3. The third part of the entry should describe; what action you took following testing, if any. Here, you should describe in detail the thought processes involved in the actions you took, and any resources you used to assist with applying the results; for example computer based systems or phone or tablet applications.

- To avoid repetition, please provide full descriptions in the first entry and if the same for subsequent days, just briefly mention

- It is important to remember that this is not a test of self-management; it is an exploration to identify avenues where patients can be assisted through future interventions. Again, it is important that you provide a reflection of your normal practices.

Day 1:   **Example of Diary Entry**

1. When did I self-monitor my blood glucose today and why:

When?	Why?
AM, Before breakfast PM, Before going out for dinner	My practice nurse told me to, a long time ago (i cant remember why) I was told to monitor twice daily and I don't like doing this in public

2. What did I do with my result following testing and why:

Result?	Why?
I wrote the AM result on a chart = 5·1 I didn't write down the evening result I don't show anyone results	The nurse had given me the chart and i sometimes fill it in. The chart wasn't handy

3. What actions did I take based on my blood glucose result, did I use any tools to assist with this and why:

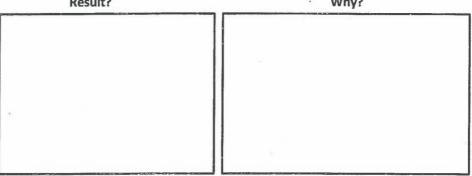| Actions/tools used?	Why?
AM - I had a large breakfast PM - I didn't do anything about this result, I think it must have been normal. i don't use any computer tools	The nurse told me to eat more when my levels are low I don't know about any tools

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Day 1:

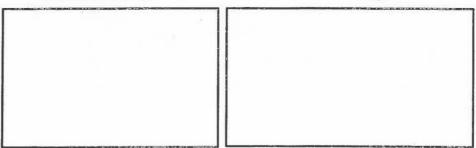**1. When did I self-monitor my blood glucose today and why:**

When?

Why?

2. What did I do with my result following testing and why:

Result?

Why?

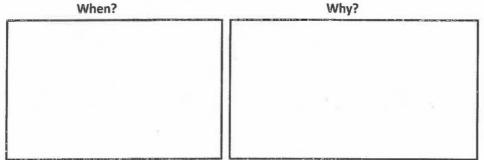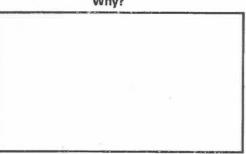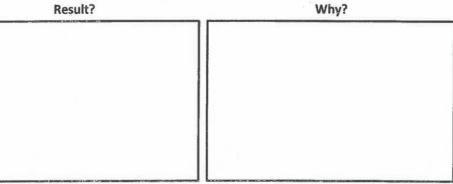**3. What actions did I take based on my blood glucose result, did I use any tools to assist with this and why:**

Actions/tools used?

Why?

Day 2:

1. When did I self-monitor my blood glucose today and why:

When?	Why?

2. What did I do with my result following testing and why:
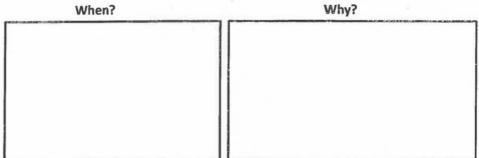
Result?	Why?

3. What actions did I take based on my blood glucose result, did I use any tools to assist with this and why:

Actions/tools used?	Why?

Day 3:

1. When did I self-monitor my blood glucose today and why:

When?	Why?

2. What did I do with my result following testing and why:

Result?	Why?

3. What actions did I take based on my blood glucose result, did I use any tools to assist with this and why:

Actions/tools used?	Why?

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Day 4:

1. When did I self-monitor my blood glucose today and why:

When?

Why?

2. What did I do with my result following testing and why:

Results?

Why?

3. What actions did I take based on my blood glucose result, did I use any tools to assist with this and why:

Actions/tools used?

Why?

Day 5:

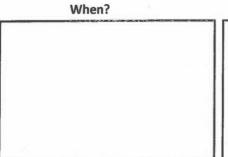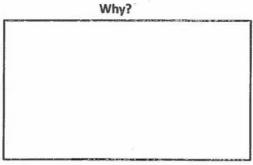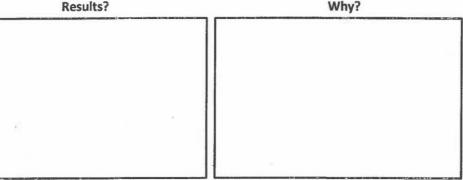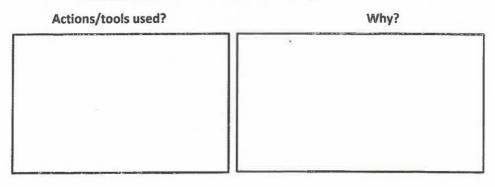1. **When did I self-monitor my blood glucose today and why:**

When?	Why?

2. **What did I do with my result following testing and why:**

Results?	Why?

3. **What actions did I take based on my blood glucose result, did I use any tools to assist with this and why:**

Actions/tools used?	Why?

Day 6:

1. When did I self-monitor my blood glucose today and why:

When?	Why?

2. What did I do with my result following testing and why:

Results?	Why?

3. What actions did I take based on my blood glucose result, did I use any tools to assist with this and why:

Actions/tools used?	Why?

Day 7:

1. **When did I self-monitor my blood glucose today and why:**

When?	Why?

1. **What did I do with my result following testing and why:**

Results?	Why?

2. **What actions did I take based on my blood glucose result, did I use any tools to assist with this and why:**

Actions/tools used?	Why?

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Appendix 6: Interview Schedule – HCPs

Appendix 10
HCP Interview Schedule protocol 002 version 2 08/10/2013

HCP INTERVIEW SCHEDULE

This interview schedule is based on research questions in conjunction with the theoretical model.

The health care practitioner will be asked questions in relation to patients in general and also in relation to the management of the patient who has identified them.

Patients understanding of their condition and associated self-management, in particular: SMBG

- What do you feel is understood with regard to SMBG, why it should form part of their self-management, how it should be undertaken and the application of results?
- What is your interpretation of clinical guidelines around SMBG and what do you recommend for patients in relation to SMBG?
- How do you feel patients rate the importance of SMBG?

Patient management practices in relation to SMBG

- What are your thoughts around 'Goal Setting' and 'Individualised Patient Care' in Diabetes Management and how do you feel this influences clinical outcomes?

How do patients undertake SMBG – Skill and Process

- What do you feel influences patients undertaking testing?
  - o Environmental influences
  - o Social influences

How do patients use results – Problem Solving Orientation

- Do patients document results, do they share these results with you and how do they generally report the results to you.
- How do you as the health care professional use the results to advise and manage the patient.
- What do patients understand about how to apply their results and how confident are they with applying their results?
- What do patients understand about glycemic patterns and how is pattern recognition being used in self-management?
- What have you experienced with regard to the tools being used for self-management, in particular web based tools and apps?
- What are your thoughts on the use of new technology in diabetes self-care in the future, could they be integrated into health care services.

Appendix 7: Interview Schedule – Support Person

SUPPORT PERSON INTERVIEW SCHEDULE

This interview schedule is based on research questions in conjunction with the theoretical model.

How well do you understand the condition; diabetes and associated self-management, in particular: SMBG

- What do you know about why patients with diabetes should self-monitor their blood glucose?
- How often should patients with diabetes SMBG?
- What can you tell me about the importance of SMBG in John's diabetes care?
- What do you know about 'Goal Setting' in the management of diabetes?

In your experience, how do patients with diabetes undertake SMBG – Skill and Process

- What influences John to undertake testing?
  - Environmental influences
  - Social influences
- What are John's difficulties around self-monitoring

How are results used – Problem Solving Orientation

- What do you know about what John does his results following testing
- How does John make decisions on actions taken following testing?
- What do you feel influences John's actions taken following testing
- Can you tell me what you know about John recognising patterns and using patterns for management of his diabetes
- Can you tell me about the tools John uses in self-management of diabetes and do you know anything about the use of new technology in testing and associated management, for example apps and web-based tools?
- What are your thoughts on the use of new technology in diabetes self-care in the future? And for John in particular?

Past learning influences on SMBG Practices

- What previous learning (diabetes related or non-diabetes related), have you had in relation to diabetes management and particularly self-monitoring of blood glucose?
- What are your experiences and thoughts around education programs in relation to SMBG?

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Past learning influences on SMBG Practices

- Have you undertaken or been involved in any education programs in SMBG (either HCP directed or patient directed)
- Have you undertaken specific training or education around goal setting in relation to self-monitoring in diabetic management and if so how has this influenced your practice?
- Can you identify any knowledge gaps around SMBG for the patient or the HCP (all disciplines).

Appendix 8: Ethics Approval

SMcC/SG

16 September 2013

UNIVERSITY OF STIRLING

SCHOOL OF
NURSING, MIDWIFERY
AND HEALTH

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Dear Dawn

Exploring the application of self-monitoring of blood glucose results in insulin treated diabetes; a case study of patients, their support persons and health care practitioners

Thank you for submitting this application, which was discussed at the SREC meeting on 11 September 2013, and for attending the meeting. We found this to be a very interesting and challenging project and we appreciated the careful thought and consideration that has clearly gone into the proposal.

I am happy to inform you that SREC has approved the study, subject to a few clarifications and queries.

These clarifications and queries we discussed on 11 September 2013 - and you seemed to have a clear grasp of these. Thank you for taking the time to meet with me.

We would request that you amend the proposal in a way that accommodates these points, and send it to me for chair's action. It would be helpful if you could put the amendments / additions in red, so that I can see the modifications at a glance. There is no need to resubmit the application to the next SREC meeting, and I will be able to respond to the amended proposal, confirming approval, within 48 hours.

Yours sincerely

Sandy McComish
(Deputy Chair)
School of Nursing, Midwifery and Health Research Ethics Committee

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EoSRES

NHS
SCOTLAND
Research Ethics Service

East of Scotland Research Ethics Service (EoSRES) REC 2
Tayside Medical Sciences Centre (TASC)
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George Pirie Way
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Mrs Dawn M Cameron
PhD Student/Research Assistant/Teaching Assistant
School of Nursing, Midwifery and Health
University of Stirling
Stirling, Scotland
FK9 4LA

Date:	16 December 2013
Your Ref:	
Our Ref:	LR/13/ES/0119
Enquiries to:	Mrs Lorraine Reilly
Direct Line:	01382 383878
Email:	Eosres.tayside@nhs.net

Dear Mrs Cameron

Study title:	**Exploring the application of self-monitoring of blood glucose results in insulin treated diabetes; a case study of patients, their support persons and health care practitioners**
REC reference:	**13/ES/0119**
Amendment number:	**AM01 (for REC reference only)**
Amendment date:	**21 November 2013**
IRAS project ID:	**138707**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

There were no ethical issues noted.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Consent Form: Patient Consent to Contact Form	2	08 October 2013
NHS REC Application Form		07 November 2013
Covering Letter		24 November 2013
Notice of Substantial Amendment (non-CTIMPs)	AM01	21 November 2013

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Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

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.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

13/ES/0119:	***Please quote this number on all correspondence***

Yours sincerely

L Reilly

pp
Dr Roberta Littleford
Alternate Vice-chair

Email: eosres.tayside@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Allyson Bailey, NHS Forth Valley
                Heather Allan, University of Stirling

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East of Scotland Research Ethics Service REC 2

Attendance at Sub-Committee of the REC meeting on 03 October 2013

Written comments received from:

Name	Position
Dr Roberta Littleford	Senior Clinical Trials Manager, Alternate Vice-chair
Mr Dougie McPhail	Primary Care Development Pharmacist

Also in attendance:

Name	Position (or reason for attending)
Mrs Lorraine Reilly	Senior Co-ordinator