Comparing and contrasting healthcare professionals' and patients' perceptions, understanding and experiences of Type 2 Diabetes (T2D) and its management. A qualitative study.

Newton, Paul

Awarding institution: King's College London

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Comparing and contrasting healthcare professionals’ and patients’ perceptions, understanding and experiences of Type 2 Diabetes (T2D) and its management: A qualitative study.

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Theses for the degree of
DOCTOR OF PHILOSOPHY
Sociology as Applied to Healthcare
2013
Abstract

Background

The increased prevalence of Type 2 Diabetes (T2D) in the UK has seen the adoption of empowerment models of T2D management. Research exists which contrasts patients’ and healthcare professionals’ perspectives of T2D management. However, no studies explicitly contrast healthcare professionals’ and patients’ perspectives within the empowerment approach.

The overall aim of this study was to explore healthcare professionals’ and patients’ perspectives of managing T2D in a context where empowerment is the prevailing health paradigm. The three research questions informing the aim sought to explore:

1) What are patients’ and healthcare professionals’ perceptions, understanding and experiences of successful and unsuccessful (un/successful) T2D management?

2) What barriers and enablers do patients and healthcare professionals perceive, understand and experience in relation to managing T2D on a day-to-day basis? and

3) What similarities and differences emerge in patients’ and professionals’ perceptions, understanding and experiences of managing T2D on a day-to-day basis?

Methods

This is cross-sectional, qualitative research using maximum-variation sampling with healthcare professional and patient participants in an empowerment-based T2D patient participation group. Semi-structured interviews (N = 25 patients / N=10 healthcare professionals), focus groups (3 x N = 12 patients) and open-ended questionnaires (N = 6 patients) were used. Data were analysed thematically using framework analysis.
Findings

Patient management of T2D developed from factors in their personal and social contexts. T2D affected patients in differing ways across the course of the illness (i.e. diagnosis, adaption and eventual self-management) and patients had different resources available in their social contexts with which to manage these effects.

Diagnosis was shaped largely by the different types of uncertainty patient participants experienced on their diagnostic route, and the progression of the illness prior to detection and diagnosis which shaped the barriers and enablers they experienced. Healthcare professionals, on the other hand saw diagnosis as a springboard to self-management and tended to interpret patients’ experiences of uncertainty as ‘resistance’. Therefore, barriers to responding to diagnosis were seen as largely patient-related.

Patient participants reported adapting to living with T2D as an ongoing process of adjusting their personal (and wider) relationships, as well as social activities, to ensure their T2D-related needs were met. Conversely, although healthcare professionals saw adaption as important, it was seen as a brief adjustment period after diagnosis and before full self-management. This highlighted another area where healthcare professionals and patients gauged successful management differently, and saw different barriers and enablers.

Patients also experienced varied barriers and enablers and evaluated successful management using diverse criteria, largely shaped by factors in their social context. Healthcare professionals expected patients to ‘own their illness’ which was seen to reduce pressure on finite health resources, and that clinical advice would create behaviour change. Healthcare professionals’ perspectives on successful self-management revolved around clinical evidence, the healthcare system and socio-contextual constraints, and portrayed barriers and enablers to managing T2D largely as patient or healthcare system related.

Discussion
Similarities and differences in healthcare professionals’ and patients’ perspectives of T2D management were seen. These occurred as a result of the fit between patients’ styles of self-management and healthcare professionals’ expectations surrounding behaviour change and health resources management. These differences were also evident during the diagnosis and adaption stages of the illness.

Conclusion

Management of T2D was seen and experienced differently by healthcare professionals and patients where empowerment of the patient to self-manage was the prevailing paradigm. The lack of fit develops largely due to the different evaluative contexts and criteria which healthcare professionals and patients use to manage T2D, and the different expectations that healthcare professionals and patients have of one another.
Acknowledgements

Thanks to Stephanie, Aidan and Owen – Love you all lots.

Thanks to my supervisors - Sasha Scambler and Koula Asimakopoulou – for going above and beyond through all the up and downs.

Thanks to all at the Unit of Social and Behavioural Sciences at KCL and colleagues at the UoG for their advice, help and support.

Special thanks to all the participants who took part in the study.
**Table of contents**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table of figures</td>
<td>9</td>
</tr>
<tr>
<td>Table of tables</td>
<td>10</td>
</tr>
<tr>
<td>Introduction</td>
<td>11</td>
</tr>
<tr>
<td>Chapter One ~ Literature review</td>
<td>21</td>
</tr>
<tr>
<td>1.1. Literature review strategy</td>
<td>23</td>
</tr>
<tr>
<td>1.2. Studies of patients’ perspectives, understanding and experiences of T2D and its management</td>
<td>25</td>
</tr>
<tr>
<td>1.3. Studies of healthcare professionals’ perspectives, understanding and experiences of T2D and its management</td>
<td>62</td>
</tr>
<tr>
<td>1.4. Studies comparing and contrasting patients’ and healthcare professionals’ perspectives, understanding and experiences of T2D and its management ('contrast studies')</td>
<td>68</td>
</tr>
<tr>
<td>Chapter Two ~ Methodology: Epistemology, Methodology and Methods</td>
<td>83</td>
</tr>
<tr>
<td>2.1. Theoretical framework</td>
<td>85</td>
</tr>
<tr>
<td>2.2. Sampling</td>
<td>89</td>
</tr>
<tr>
<td>2.3. Data collection</td>
<td>95</td>
</tr>
<tr>
<td>2.4. Data analysis</td>
<td>106</td>
</tr>
<tr>
<td>2.5. Reflexivity, validity and reliability strategies</td>
<td>110</td>
</tr>
<tr>
<td>2.6. Ethical issues</td>
<td>112</td>
</tr>
<tr>
<td>Chapter Three ~ Findings 1: Profile of participants &amp; Diagnosis of Type 2 Diabetes</td>
<td>114</td>
</tr>
<tr>
<td>3.1. Profile of participants</td>
<td>116</td>
</tr>
<tr>
<td>3.2. Patients’ perceptions, understanding and experiences of T2D diagnosis</td>
<td>123</td>
</tr>
<tr>
<td>3.3. Healthcare professionals’ perceptions, understanding and experiences of T2D diagnosis</td>
<td>141</td>
</tr>
</tbody>
</table>
3.4. Comparing and contrasting patients’ and healthcare professionals’ perceptions, understanding and experiences of T2D diagnosis.................................................................149

Chapter Four ~ Findings 2: Adaption to living with Type 2 Diabetes.........................153

4.1. Healthcare professional participants’ perceptions, understanding and experiences of adapting to living with T2D.............................................................................................................155

4.2. Patient participants’ perceptions, understanding and experiences of adapting to living with T2D...............................................................................................................................157

4.3. Comparing and contrasting patient and healthcare professional participants’ perceptions, understanding and experiences of T2D diagnosis...........................................................198

Chapter Five ~ Findings 3: The management of Type 2 Diabetes..................................205

5.1. Patient participants’ perceptions, understanding and experiences of managing T2D...206

5.2. Healthcare participants’ perceptions, understanding and experiences of managing T2D......................................................................................................................................................246

5.3. Contrasting healthcare professional and patient participants’ perceptions, understanding and experiences of managing T2D...........................................................................................................258

Chapter Six ~ Discussion..................................................................................................265

6.1. What are patients’ and healthcare professionals’ perceptions, understanding and experiences of successful and unsuccessful (un/successful) T2D management?..............................268

6.2. What barriers and enablers do patients and healthcare professionals perceive, understand and experience in relation to managing T2D on a day-to-day basis?.................................276

6.3. What similarities and differences emerge in patients’ and professionals’ perceptions, understanding and experiences of managing T2D on a day-to-day basis?................................283

6.4. Methodological strengths and limitations of the present study...............................286

6.5. Areas for further research..........................................................................................291

6.6. Practical applications of the work..............................................................................292

Conclusion.......................................................................................................................295

Bibliography.....................................................................................................................298
Appendix One ~ Literature review supplement..............................................................335
Appendix 1a: Literature review search terms..............................................................336
Appendix Two ~ Data collection supplements............................................................337
Appendix 2 a: Introductory cover letter for patient participants.................................338
Appendix 2 b: Patient participant information sheet (for questionnaires, focus groups and interviews)...............................................................................................339
Appendix 2 c: Consent form (all patient and healthcare professional participants)........342
Appendix 2 d: Topic guide for patient participant focus groups..................................343
Appendix 2 e: Topic guide for patient participant interviews......................................345
Appendix 2 f: Patient participant questionnaire.........................................................347
Appendix 2 g: Patient participant ‘About you’ sheet (for gathering questionnaire, focus group and interview participants’ socio demographic data).................................355
Appendix 2h: Introductory cover letter for healthcare professionals..........................356
Appendix 2 i: Healthcare professional participant information sheet..........................357
Appendix 2 j: Topic guide for healthcare professional participant interviews...............359
Appendix 2 k: Research questions with pathway to corresponding data collection tool question number (and comparable questions)..................................................361

Appendix Three ~ Published articles in peer-reviewed journals..................................362


# Table of Figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1</td>
<td>The three domains of the real in critical realism</td>
<td>86</td>
</tr>
<tr>
<td>Figure 2</td>
<td>The research process</td>
<td>97</td>
</tr>
<tr>
<td>Figure 3</td>
<td>Themes from healthcare professionals’ accounts of diagnosis</td>
<td>146</td>
</tr>
<tr>
<td>Figure 4</td>
<td>Patient participants’ causal understandings of T2D – How causal sources and contributory factors are combined</td>
<td>143</td>
</tr>
<tr>
<td>Figure 5</td>
<td>The 3-part iterative process of adjusting use of time to adapt to living with T2D</td>
<td>178</td>
</tr>
<tr>
<td>Figure 6</td>
<td>Themes in patient participants’ perceptions, understanding and experiences which comprise the adaption process</td>
<td>192</td>
</tr>
</tbody>
</table>
Table of tables

Table 1: Socio-demographic characteristics of sample..........................................................118
Table 2: Roles of healthcare professional participants and number of participating...............121
Table 3: Route to diagnosis, with reported statuses of symptoms and patient responses.........138
Table 4: Healthcare professionals’ perceptions of successfully managing T2D and perceived barriers and enablers by theme.................................................................148
Table 5: Patients’ motives for self-management with associated gauges of successful and unsuccessful management..........................................................208
Table 6: Areas of self-management and associated barriers, enablers and neutralisers.........215
Table 7: Styles of patient participant self-management with associated motives, indicators of un/successful management, role expectations, style of information use and socio-demographic characteristics.........................................................243
Table 8: Previous typologies of patient self-management, gauges of un/successful management and typology of current study. .................................................................272
Table 9: Literature review terms and search strategy (Appendix 1a)........................................336
Table 10: Research questions with pathway to corresponding data collection tool question number and comparable questions (Appendix 2 j).........................................................361
Introduction

Type 2 Diabetes in context:

Diabetes Mellitus is a definition given to a group of heterogeneous metabolic disorders characterized by elevated blood glucose concentration (Foundation of European Nurses in Diabetes (FEND), 2011). Diabetes Mellitus is classified in a number of ways, the most prevalent categories being Type 1 Diabetes (T1D) and Type 2 Diabetes (T2D). Generally T1D occurs when there is no production of insulin produced in the beta-cells of the pancreas, which results in elevated blood glucose levels and the need to frequently administer of exogenous insulin (O’Rahilly, 2006). In the majority of cases onset of T1D occurs in childhood. T2D, on the other hand is generally associated with onset in later life – and as a loss of response to the action of insulin, known as ‘insulin resistance’ as well as beta cell destruction (FEND, 2011). In 2010, Diabetes UK (2010) estimated that there were 2.6 million people diagnosed with diabetes in the UK, 90 per cent (n=2,213,136) of whom had T2D (the remaining 10 per cent having T1D).

In all types of Diabetes Mellitus, it is the body’s inability to produce or respond to insulin which increases blood glucose concentration, this causes the blood to thicken which adversely affects the systemic functioning of the body - particularly the circulatory system (FEND, 2011). This leads to the symptoms and further pathologies of Type 2 Diabetes. The morbidities of diabetes are predominantly micro- and macro-vascular in nature, and can result in severe complications such as cardio-vascular disease, blindness and amputation (O’Rahilly, 2006). T2D is, hence, associated with higher morbidity rates across the lifespan (Diabetes UK, 2010). Diabetes is the fifth most common cause of death globally (World Health Organisation (WHO), 1999), and in England more than one in ten (11.6 per cent) deaths among 20 to 79 year-olds can be attributed to diabetes (Diabetes UK, 2010).
Diabetes is a long-term condition which affects multiple areas of daily life, and as such must be managed on a day-to-day basis by the diagnosed individual, often with the help of their family and/or carers. Day-to-day management includes self-care tasks such as monitoring blood sugars, regular exercise, following prescribed dietary measures, and medication-taking (oral and exogenous insulin therapies). When this set of behaviours occurs the patient is said to be self-managing their condition. As a long-term condition, T2D represents a case where early diagnosis is crucial to good health outcomes, and where the ability to respond to the illness through ‘lifestyle changes’ and medication taking - as well as access to healthcare information and service provision - has an ameliorative effect on health outcomes in terms of quality of life, morbidity and mortality (British Medical Association (BMA), 2004; Diabetes UK, 2010; FEND, 2011).

There is growing concern surrounding the high prevalence of T2D, in particular high mortality rates and shortened life expectancy (Department of Health (DoH), 2002; O’Rahilly, 2006; Diabetes UK, 2010). In the UK life expectancy is shortened on average by up to 10 years for T2D (Diabetes UK, 2010). The adverse impact of T2D also extends to the effects that complications can have on people’s lives - around half of all people living with T2D are living with complications, many of whom often developed complications before diagnosis (Diabetes UK, 2010). The burden of the disease that T2D represents for health systems is also a concern – with costs to the UK National Health Service (NHS) estimated to be around £1 million an hour (Diabetes UK, 2010).

One factor contributing to high prevalence of T2D in the UK is an ageing population. Risk factors for T2D increase with age, hence, overall rates rise as the population ages. One-in-twenty people over 65 years of age have T2D, rising to one-in-five for those 85 years or above. Therefore, recent national initiatives have focussed on screening the elderly population at the primary care level (NHS Diabetes, 2013). However, other social factors have also shown to play a role. For example, in those under the age of 65, ethnicity has also been identified as a factor in the prevalence of T2D.
particularly in those of an African-Caribbean or Asian origin - a three- to six-fold increased prevalence respectively when compared to the white population (NSF, 2002). T2D has a more common prevalence in socio-economic groups with lower incomes – The British Medical Association link this prevalence in both cases to low birth weights and obesity brought about by poor diet (BMA, 2004). Hence, interventions tend to target individuals who are seen to have deficits in healthy behaviours. However, the social patterning of wider illness by socio-economic status is well established in the UK literature, the main factor implicated being unequal access to health-protective resources due to mal-distribution of wealth (Scambler, 2009). In the North East of England, for example, T2D prevalence is 28% higher for men and 45% higher for women in the most deprived areas, compared to the regional average. So too, people living with T2D have a higher risk of both morbidity and mortality which is further exacerbated and confounded by ethnicity, class and increased age (Connolly, 2006; NHS National Diabetes Service, 2012). More recent data suggests that variations in morbidity and mortality are not associated with lifestyle alone, but rather access to health promoting resources and disparities in healthcare provision (NHS National Diabetes Service, 2012).

**Managing T2D:**

As we have seen the determinants of diabetes are multi-factorial. Van Dam et al (2003) and Nam et al (2011) argue that blood glucose level is the most commonly researched dimension of diabetes management. In fact this aspect of diabetes research is the primary focus of some of the largest national studies of diabetes such as The Diabetes Control and Complications Trial Research Group (DCCT: 1993, 1996) and the United Kingdom Prospective Diabetes Study (UKPDS, 1999). The main thrust of these studies is that maintaining control of the metabolism through strict adherence to dietary, insulin and noninsulin therapy, and regular exercise can ameliorate symptoms of diabetes, as well as delay and decelerate complications. Although prevalence can inform service provision and the deployment of health resources, the vast majority
of managing T2D is conducted on a day-to-day basis by people living with diabetes (self-management or patient management of T2D). Therefore, there is also growing concern with the frequently poor ‘adherence’ or ‘compliance’ to diabetes-related regimens in spite of public health interventions (Lawton et al., 2003).

Psychological research points to affective, cognitive and behavioural aspects which influence the capacity to self-care. Research in this vein investigates how factors such as personality and behavioural dispositions (Knight, Dornan and Bundy, 2006); belief in the ability to perform a task – or self-efficacy (Funnell and Anderson, 2004; Anderson et al., 2009); and perception of risk (Asimakopoulou et al, 2008), to name but a few, all influence patients’ capacity to self-manage. As such, ‘control’ and ‘management’ of T2D are measured as maintaining a blood glucose level as close to that of the population without diabetes as possible. In contrast to these studies, Diabetes UK (2003) note that although such studies show utility in justifying or evaluating clinical courses of action, they do not take into consideration the personal and social barriers people experience in attaining, and maintaining adherence to the therapeutic regime. Hence, a growing body of research is also developing which seeks to enhance studies of prevalence and adherence by looking at psycho-social aspects of T2D. A key drive in these studies is to explore factors that inhibit or enhance the capacity of people living with T2D to self-manage, and to investigate factors that constrain and enable access to supportive social environments that improve health (Gomersall et al., 2011).

*Type 2 Diabetes and empowerment in policy and practice:*

Over the course of the past 25 years, a sea-change in the philosophy informing Type 2 Diabetes (T2D) management has occurred. This was due in part to evidence suggesting that the previously dominant ‘adherence model’ of T2D management was ineffective, as well as unpopular with providers and patients alike (Funnell et al., 1991; Cyrino et al., 2009). One overriding criticism of
the adherence model was that it defined, and sought to change, patient behaviour based solely on how closely patients followed clinically recommended behaviours (Hunt and Arar, 2001). As such, very little consideration was given to the barriers patients experienced in carrying out clinically-recommended advice, how appropriate professional recommendations were to the day-to-day lives of people living with T2D, or to how healthcare professionals themselves contributed to ‘non-adherence’ behaviour (Hunt and Arar, 2001).

The adherence approach to patient care has since been supplanted by empowerment models which seek to create an equipoise situation whereby professionals’ clinical and bio-medical expertise and patient ‘lay’ expertise complement one another in the management of T2D (Asimakopoulou et al., 2012). Empowerment, as a concept, is based on the assumption that individuals, if given the freedom to choose and the opportunity to reflect, will be able and willing to select appropriate diabetes goals – which can then be facilitated by the healthcare professionals’ knowledge of the clinical realm.

The prevalence of the empowerment model has grown not only within the T2D research literature, but in practice - with the majority of current clinical approaches, self-management support and T2D health education (in developed healthcare systems) purporting to adopt empowerment models (Forbes et al., 2010). The empowerment approach became a central plank of diabetes management (i.e. patient self-management and clinical management ofT2D by healthcare professionals) in the UK with the full adoption of the National Service Framework (NSF) for Diabetes in 2003 (DoH, 2001; Henshaw, 2006). The NSF set standards for healthcare professionals and health services ‘empowering’ people to self-manage T2D which patients could expect from services. This emphasis on patient-led, self-directive approaches which promote shared-decision with healthcare professionals – a direct challenge the adherence model – can be linked to wider trends in European healthcare which seek to involve patients in healthcare decision-making (Coulter, 2002). Its adoption in T2D management is also linked to the oft cited
assertion that although professionals are the clinical experts in T2D management, patients are experts in living with diabetes by virtue of managing T2D on a day-to-day basis (Nam et al, 2011; Corser; 2010).

However, the evidence base for the empowerment model is still inconclusive and there is concern amongst commentators that many of the positive clinical and behavioural outcomes are short term in nature (Henshaw, 2006). Knight et al. (2006), note in a major critique of the approach that whilst T2D patients may be happier with their care, this gain may be at the expense of health outcomes. Others suggest that the adoption of empowerment approaches in T2D constitutes a transference of the burden of care to the patient who may not be able to cope with this burden, and which engenders moral and ethical issues which have not been addressed (Asimakopoulou, 2012; Redman, 2007). Critique has also focussed on the role of healthcare professionals in the empowerment paradigm. Asimakopoulou et al. (2012) have noted that within healthcare practice and the empowerment literature itself, focus has shifted to patients’ perceptions, understanding and experiences of living with T2D, but the emphasis then tends to relate empowerment-based interventions to the clinical, affective and behavioural indicators of successful management.

In a systematic review of empowerment, diabetes and the values of the NSF, Henshaw (2006) found a dearth of studies looking at professional perceptions of, and experiences of delivering the patient empowerment agenda in T2D. However, secondary research on the barriers to diabetes management, support the emphasis on patient behaviour change in the empowerment literature. Findings suggest that focussing interventions on healthcare professional behaviour-change are less effective at improving patient self-management and outcomes (van Dam et al., 2003) and less effective at reducing barriers to diabetes management (Nam et al., 2011) than other patient-focussed interventions. The aforementioned studies found that interventions focusing on
improving provider consultation styles found a correspondence between poor healthcare professional communication and low treatment adherence (Nam et al. 2011; van Dam et al., 2002). Although there is some T2D empowerment training for healthcare professionals, as part of the DESMOND educational package in the UK for example, there is an assumption that healthcare professionals will generally be able to adapt to this new way of working and managing T2D (Asimakopoulou, 2007).

*Rationale for this research:*

As we can see the empowerment approach involves healthcare professionals working ‘in partnership’ with patients to develop skills which will enable patients to self-manage (the term patient is used here, and throughout, to denote them as participants within the research independent from healthcare professional participants). One international study, the Diabetes Attitudes, Wishes and Needs (DAWN) study looked at healthcare professionals’ and patients’ (living with both Type 1 and 2 Diabetes) experiences of managing T2D. It was found that the major challenges to diabetes care were overcoming patient psychological problems, poor adherence to treatments and lack of resources for healthcare professionals (Peyrot et al., 2005). Conversely, and in terms of empowerment, a large body of work has been developed to capture patients’ perceptions, understanding and experiences of living with and self-managing T2D. This work has both informed and critiqued the empowerment approach. This patient-related literature tends to highlight barriers and enablers patients experience in self-management, and distil factors which patients use to evaluate their self-management. These accounts provide explanations of how factors in the patient’s day-to-day life, their attitudes towards health and wider socio-contextual issues, shape self-management. This suggests that self-management cannot be reduced to patient behaviour as was the case with the DAWN study (Peyrot et al., 2005).
Equally, little is known about healthcare professionals’ experiences of practicing empowerment (e.g. Asimakopoulou et al., 2011, Scambler et al 2012) – despite healthcare professionals forming half of the empowerment ‘partnership’. However, more recent work than the DAWN study (Peyrot et al., 2005), has shown that healthcare policy, the attitudes of healthcare professionals and their application of the empowerment approach, as well as wider social issues all contribute to healthcare professionals’ views of managing T2D – suggesting the focus on patient behaviour is reductionist (Newton and Asimakopoulou, 2008; Asimakopoulou et al., 2011).

A small body of work also exists which compares and contrasts patients’ and healthcare professionals’ experiences of managing T2D. These studies look at how the process of managing T2D is shaped by convergence and/or divergence in patients’ and healthcare professionals’ perceptions, understanding and experiences. The empowerment approach, with its central emphasis on partnership, would appear to be an area that would benefit from this type of research. However, no research was found in the literature that has explicitly compared and contrasted healthcare professionals’ and patients’ perceptions, understanding and experiences of managing T2D where empowerment is the prevailing approach.

Aim and research questions:

The present research responded to prevailing trends in T2D-management and the gap identified in the literature. The aim of the present research was to compare and contrast the perceptions, understanding and experiences of healthcare professionals practicing T2D management within the prevailing empowerment paradigm and the perceptions, understanding and experiences of people
living with, and self-managing, T2D within a healthcare context informed by the paradigm. Following a review of pertinent literature three research questions were developed:

1) What are patients’ and healthcare professionals’ perceptions, understanding and experiences of successful and unsuccessful (un/successful) T2D management?
2) What barriers and enablers do patients and healthcare professionals perceive, understand and experience in relation to managing T2D on a day-to-day basis? and
3) What similarities and differences emerge in patients’ and professionals’ perceptions, understanding and experiences of managing T2D on a day-to-day basis?

**Overview of Chapters:**

The first chapter reviews the current literature on healthcare professionals’ and patients’ perceptions, understanding and experiences of managing T2D. The review incorporates three strands of literature:

- Patients’ perceptions, understanding and experiences of managing T2D (with subsections highlighting diagnosis, adaption and self-management);
- Healthcare professionals’ perceptions, understanding and experiences of managing T2D; and
- Studies comparing and contrasting patients’ and healthcare professionals’ perceptions, understanding and experiences of managing T2D (‘contrast studies’).

Chapter 2 describes the methodological tenets of the research. After discussing the theoretical framework of the study, it moves on to the sampling aims and recruitment strategies employed. The data collection and analysis techniques adopted and the justificatory
assumptions underpinning the adoption of these techniques are then outlined. The chapter also briefly outlines the strategies put in place to promote validity and reliability of data, and looks at how ethical issues were addressed.

The findings of the research are presented in Chapters 3, 4 and 5. Chapter 3 first reports the socio-demographic characteristics of the sample, as well as the findings relating to managing T2D diagnosis. Chapter 4 presents the findings relating to how adaption to T2D is managed, and Chapter 5 looks at the actual day-to-day management of T2D by healthcare professionals and patients. Each of these ‘findings chapters’ present the findings relating to patients’ accounts, and then healthcare professionals’ accounts before comparing and contrasting them.

Chapter 6 discusses the contribution of this thesis to the literature whilst answering each of the research questions. This chapter also outlines the methodological strengths and limitations of the study, and highlights potential areas for future research. A brief conclusion highlighting the key points of research is given following the discussion.
Chapter One – Literature Review

Contrasting healthcare professionals’ and patients’ perspectives, understanding and experiences of Type 2 Diabetes (T2D) and its management.

Chapter headings:

Introduction 1.1. Literature Review Strategy

1.2. Studies of patients’ perspectives, understanding and experiences of T2D and its management

1.3. Studies of healthcare professionals’ perspectives, understanding and experiences of T2D and its management

1.4. Studies comparing and contrasting patients’ and healthcare professionals’ perspectives, understanding and experiences of T2D and its management (‘contrast studies’)
Introduction

This literature review was conducted in order to determine the key research themes and findings in studies, mainly within sociology of health and illness, which contrast healthcare professionals’ and patients’ perspectives of the management of T2D - from 2000 onwards. Literature of a seminal influence, preceding 2000, was also identified where papers were cited repeatedly (greater than 5 times) within the literature and included in the final sift of articles (e.g. see Cohen et al, 1994). However, within the literature searched, no studies that explicitly contrasted patient and professional views and experiences of managing T2D within a context explicitly underpinned by the empowerment approach were found. Although a body of work exists relating to clinical, affective and behavioural aspects of T2D management, which use clinical and psychological constructs to measure perception and behaviour, this review sought to capture studies of patients’ and healthcare professionals’ lived, self-reported experience of managing T2D. Studies of empowerment in T2D care, for example, tend to measure the impact of empowerment interventions in a proxy fashion through changes in reported emotional distress using instruments such as Problem Areas in Diabetes (PAID) scale (e.g. Anderson, 2009); or diabetes-related knowledge using instruments such as the Diabetes Knowledge Scale (e.g. Collins et al., 2011). However, the present study sought to explore T2D and the management of T2D through the everyday perceptions, understanding and experiences of healthcare professionals and people living with T2D.

This chapter begins by describing the strategy adopted to collect literature, before moving on to present the findings of the search. The first section presents a synthesis of the literature on patients’ experiences of living with and self-managing T2D. The next section of the review looks at healthcare professionals’ views of T2D self-management. Finally, the chapter concludes by
reviewing the literature of studies that compares and contrasts patients’ and healthcare professionals’ views of managing T2D.

1.1. **Literature Review Strategy**

The aim of the literature review was to provide a thematic overview of empirical evidence and current developments in research exploring patients’ and healthcare professionals’ experiences, understanding and perceptions of managing T2D. Focussed literature searches were undertaken to identify and retrieve literature relating to the following strands:

- People living with T2Ds’/patients’ experiences, understanding and perceptions of managing T2D;
- Healthcare professionals’ experiences, understanding and perceptions of managing T2D;
- Contrasts/comparisons of people living with T2Ds’/patients’ and healthcare professionals’ experiences, understanding and perceptions of managing T2D.

A search was conducted of keywords, titles and abstracts for journal articles (including secondary resources, such as concept clarifications; systematic and generic literature reviews) on Pubmed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Applied Social Sciences Index and Abstracts (ASSIA) and Scopus databases from January 1, 2000-onwards. This time frame was imposed on the literature search to capture literature on (self-) management of T2D over a period of time where empowerment became a prevailing influence on the policies and practices of modern healthcare systems, and where empowerment informed healthcare delivery and T2D research (Henshaw, 2006; Watt and Ponto, 2008). Initial searches took place in
November 2006, and were regularly updated over the course of the study. A complete table of the terms and search strategy can be found in Appendix 1a.

**Inclusion criteria**

The material identified by the searches was examined for inclusion. The aim was to include the full range of relevant materials to provide a concise thematic summary of current knowledge. Where existing reviews were available these were used to enhance the coverage of the broad areas of activity identified. The formal literature was divided into those providing an empirical assessment and those offering a theoretical or analytical perspective of living with, and managing, T2D. The specific inclusion criteria were that the item had relevance to:

- The identified topic area – Patients’ and healthcare professionals’ *self-reported* experiences, perceptions and understanding of T2D, i.e. articles using predominantly *proxy measures* or validated instruments (e.g. metabolic outcomes; self-care impact; psychological variables; and service outcomes) as measures of perception and behaviour were excluded.

- T2D, i.e. articles referring solely to Type 1 Diabetes were excluded;

- The time span of 2000 onwards.

The period from 2000 onwards was chosen to capture the period where empowerment approaches became a statutory obligation in the practise of managing T2D in the UK health service - with the establishment of the National Service Framework for Diabetes (Department of Health, 2001). Secondary research was included, as were relevant citations in reference lists that were not captured in the search. Material of seminal influence, preceding 2000 and with repeated citation within the literature was also included (as discussed above).

**Data extraction and management**
Once duplicates were removed and selection criteria applied, the remaining articles were read repeatedly. The key data extracted from the empirical studies and secondary research included: description of study; type and target population; details of the typology or perceptual behaviour and influences relating to managing and living with T2D, including any underpinning theory (Hart, 2002). The ideas and models identified from theoretical papers were incorporated directly into the thematic structure of the literature review. Extracted content was then read and organised within three areas (patient-related, professional-related and contrast studies). The aim was to develop thematic areas across the literature to identify the emerging conceptual areas, methodological issues and areas of further study, rather than synthesizing elements of the study to create new concepts through meta-synthesis (Cronin et al., 2008; Campbell et al, 2003).

1.2. Patients’ perspectives, understanding and experiences of T2D and its management

This broad category of literature consists of predominantly qualitative studies looking at patients’ experiences of illness, as an experience in everyday life often in contrast to the bio-medical, psychological and epidemiological models of causation, patterning, and adherence. There is strong resonance between the literatures pertaining to patient perspectives with the patient empowerment models of T2D management. As such self-management refers to the care activities people living with T2D adopt in order to manage their condition. Empowerment, following Asimakopoulou (2007), refers to ways that power differentials and care responsibilities are dispersed between patients and healthcare professionals, and ways in which patients are encouraged or expected to self-care. Empowerment-based studies have both informed the development of empowerment over the years and charted its relative successes and shortcomings. Literature on patient perspectives of managing T2D has tended to flow contrary to traditional
models seeking to understand non/adherence, in favour of gaining an understanding of the role of personal and social factors shaping the management of chronic illness, i.e. self-management (Lawton, 2003).

Evidencing the growth in research studies and policy addressing patients’ experiences of living with T2D, these studies formed the bulk of this literature review. To manage this literature in a more systematic manner, the studies were synthesised using three key heuristic areas relating to the process of managing T2D – identified inductively from repeated reading of the literature. The three areas identified were:

Patients’ perspectives, understanding and experiences of:

- T2D diagnosis (1.2.1);
- Understanding and experiences of adapting to T2D (1.2.2); and
- Managing T2D in a day-to-day context (1.2.3)

These areas are overarching; therefore many of the studies extracted in the patient-related literature search cross over these areas, whilst some studies remain within a single, discrete area. However, clear themes and arguments develop within these heuristic areas so the results of the review are presented thematically within these analytical areas. This is done to develop a thematic framework to aid understanding of the literature on healthcare professionals’ experiences of managing T2D and studies contrasting patients’ and professionals’ perspectives.

1.2.1. Patients’ perspectives, understanding and experiences of T2D diagnosis
Both Hiscock et al. (2001) and Peel et al. (2004a) describe ‘routes’ to T2D diagnosis, these were: ‘suspected diabetes’ route; ‘illness’ route; and ‘routine’ route. The route to diagnosis encountered by the individual was seen to have causal relationships with the emotional reactions to the illness as well as initial ability to absorb educational information. Hiscock et al’s (2001) study is significant within the literature as its findings informed the development of the National Service Framework for Diabetes (Department of Health, 2001) which promoted the empowerment of patients. The authors suggested that patients initially experienced a period of reacting to the diagnosis, rather than responding to the implications of the diagnosis. As such, Hiscock et al. (2001) recommended that too much information at the time of diagnosis was not considered appropriate or helpful by patients. Factors cited by patients as influencing their response to diagnosis were:

- The extent to which the news was expected
- Experience and knowledge of diabetes
- The way the diagnosis was handled by health professionals
- Type and amount of information provided about the condition.

(Adapted from Hiscock et al: 2001)

In Hiscock et al’s study there was a notable bias in recruitment of patients from a Diabetes UK helpline, i.e. people actively seeking information on T2D self-management were recruited. Seeking information may have been a result of this group experiencing their diagnosis as a shock, rather than T2D diagnosis being a shock in all diagnoses. Peel et al. (2004a) found that this assertion of a global ‘shock’ period post-diagnosis was presumptuous. Peel et al (2004) found three routes to diagnosis: the ‘suspected diabetes’ route; ‘illness’ route; and ‘routine’ route. Rather, the different routes to diagnosis held sway over emotional responses, and reactions to diagnosis.
were more complex and diverse than ‘shock’ scenarios. The study found that patients’ requests for information at diagnosis were frequently unrelated to ‘emotion’. In the case of a ‘routine testing’ diagnosis, the ‘seriousness’ of the illness was often determined by the amount and type of information and services that patients received. In the ‘suspected diabetes’ route, diagnosis was often a relief, as it was in the ‘illness route’ – although some in the ‘illness route’ reported initial shock, then relief. In the same study, Parry et al. (2004) found that diagnosis is a crucial (under-used) point of learning in T2D self-management, and that the clarity, timing and authority of the diagnosis by healthcare professionals shaped patients’ emotional responses. The advantage of this study is that it was a prospective, longitudinal study that followed participants, noting how the roles and positions they adopt change over time. Rather than drawing on theoretical standpoints to explain participants’ viewpoints, this programme of study tracked the process of how patient understanding - and ways of managing T2D - changed over time (Peel et al., 2004a; Parry et al. 2004; Gomersall et al., 2011) to show common processes. Route to diagnosis was found to shape participants relationships with T2D self-management.

Eborall et al. (2007) argue that whereas quantitative findings give little import to the significance to the diagnostic route of the patient, qualitative work has shown that people diagnosed through routine checks took T2D less seriously than those diagnosed as a result of, for example, hospital admission. Eborall et al.’s (2007) study showed that perceptions of the illness changed over the process of diagnosis, and that it was possible to facilitate psychological adjustment through having clear information at the time of T2D screening or diagnosis, and follow up information for patients. The type and amount of information throughout diagnosis was also significant –Eborall et al. (2007:458) conclude that professionals must “…convey enough information about the potential consequences of the disease to justify lifestyle change, without raising anxiety sufficiently to cause disengagement”. However, the structured procedures associated with the screening and diagnosis of T2D usually have time gaps which may provide reflective time where
patients can reflect on their response to diagnosis a priori, or seek information to allay their concerns. The prospective component of Eborall’s (2007) study – interviewing at points throughout the screening process – highlighted this process of adjustment. However, the opt-in nature of research and of screening processes (i.e. that characterize this study sample, n=23) may affect the generalizability of this research. This is because the sample may be comprised predominantly of participants who wanted clarity about, or had an interest in, their current status of their health and would thus respond positively to information-giving. Eborall et al’s finding that the delivery of diagnosis influenced patient response to diagnosis is borne out. Polonsky et al (2010) investigated levels of distress patients experienced at the time of diagnosis then measured levels of distress alongside clinical indicators of self-management 1-5 years later. It was found that where patients reported that healthcare professionals offered reassurance and a clear care plan at the time of diagnosis, less distress was experienced by the patient. This effect was found to be long-lasting with those receiving this type of guidance from professionals, having less distress and better self-management outcomes 1-5 years later. One limitation of Polonsky et al’s (2010) study was the retrospective reporting of experiences of diagnosis, i.e. whether the participants’ post-diagnosis, cross-sectional accounts of their diagnosis accurately reflected their original experiences. However, the study found no differences in findings when comparing responses by length of time since diagnosis –suggesting that deteriorating recall of events did not occur.

Lawton et al. (2005a) found that, following diagnosis, patients felt that they lacked the confidence and knowledge to manage T2D, and often wanted quick access to services. The patients interviewed also showed a preference for primary care services, particularly services provided by GPs and practice nurses, as this gave them more time to discuss the issues they had. Troughton et al. (2008) looked at patients with a diagnosis of ‘pre-diabetes’ and found that their experiences were characterised by uncertainties about their diagnosis, which related to its physical
consequences and subsequent management. The study also found that patients sought certainty by reading into healthcare professionals’ responses in clinical encounters as a gauge of how serious the condition was. However, Weinger et al. (2006) found that patients described a ‘backburner’ phase following diagnosis where they felt well, and didn’t prioritize diabetes over other issues in their life. Lawton et al’s (2005a, b), Troughton et al’s (2008) and Weinger et al’s (2006) studies focus on the experiences of *asymptomatic*, newly-diagnosed T2D patients. Hence, these studies essentially exclude the experiences of those diagnosed through other routes, e.g. hospitalisation. Also Lawton et al’s (2005a, b) study takes place at a time of service change in Scotland, a transition of clinical management of T2D from secondary care to primary care. Lawton et al’s (2005a, b) study concluded that previous experiences of service provision and patients’ causal understandings of the T2D informed their preferences for services. However, the majority of respondents in this study were asymptomatic, meaning that those diagnosed by different routes and/or at different points in the trajectory of T2D may have different preferences for services (having had frequent engagement with services already), and may not experience a period characterised by uncertainty following their diagnosis.

In overview, looking at responses to diagnosis from the patient’s perspective it would appear that although there may be a period of shock to diagnosis, this may not be the norm. Rather, routes to and delivery of the diagnosis – and information given at the time of diagnosis - are influential factors in patients’ perceptions, understanding and experiences of diagnosis - albeit demonstrated solely in asymptomatic, newly diagnosed patients. Hence routes to diagnosis have been shown to influence response to diagnosis in the short-term and to impact on self-management outcomes in the long-term. Less is known about how the different mechanisms work in different routes to diagnosis. Routes to diagnosis have also been shown to influence how seriously the patient considers the condition to be, and shape health outcomes in later years. Having previous
experience of diabetes also appears to shape understanding and responses at the time of diagnosis. It is also clear that patients experience uncertainty at the time of diagnosis which influences the type of information and services they would like to receive. This uncertainty can also lead to patients looking for external cues – in professional attitudes and actions – to assess the significance of T2D. However, there are gaps in understanding how progression of the illness at the time of diagnosis has on people’s experiences of diagnosis.

1.2.2. Patients’ perspectives, understanding and experiences of adapting to T2D

Bury’s (1982) seminal work in biographical disruption argued that the diagnosis (or onset) of chronic illness constitutes a rupture in the linear flow of a person’s life. When disruption occurs, taken-for-granted abilities and activities are threatened including personal views such as self-concept and identity. This process necessitates a re-evaluation and renegotiation of these practical, personal concerns, as well as the social concerns the person has, i.e. the process of adaption is intrinsically gauged both inwardly (personal) and in an outward manner (social). In terms of social effects, Lawton (2003:32) summarises this as patients gauging: “the importance of ‘external’ resources (interpersonal, structural and material) to the ways in which illness is experienced and lived out...”. Using Bury’s (1982) notion of biographical disruption, Hörnsten et al. (2004) explored the consequences of T2D on sufferers’ everyday lives. The study demonstrated that getting a diagnosis of T2D, or information about T2D from a medical professional was different from “getting diabetes”, i.e. integrating the disease into the aspects of everyday life (Hörnsten et al., 2003:180). The authors found six key areas of concern relating to adapting to living with T2D:
• How the patient balanced their previous experience of the disease with their current experience;
• The impact of diagnosis;
• Creating routines to integrate the illness into their daily lives;
• The value and priority given to the illness;
• How division/s of responsibility for care between self and others are negotiated;
• The impact of the illness on future prospects

(Adapted from Hörnsten et al., 2004)

Echoing Bury, Hörnsten et al. (2004) suggest that understanding patients’ experiences of adaption to illness should focus on meanings attached to the illness - as generated in a personal and social context - which are crucial to understanding the adaption and management processes in T2D.

It is worth noting, however, that medical sociological literature following Bury - particularly the work of Williams (1984) - extended and critiqued aspects of Bury’s work. Williams’ (1984) study in narrative reconstruction showed why and how people’s understandings focused on the cause of their illness, and how these were interwoven with personal histories, and the need to develop a secure and valued identity. The work of Williams (1984) explores how narratives are reconstituted through ‘narrative reconstruction’. The concept of narrative reconstruction suggests that those with chronic illness develop a biographical understanding of the aetiology and management of their illness “…linking and interpreting different aspects of biography in order to realign present and past, and self and society.” (Williams, 1984:197). For Williams (ibid), understanding of illness causation, management and consequences changes over time, with people adjusting narratives to portray their actions in a positive moral light. In Williams’ study lay causative understandings were interwoven with stories of their background, family relations, fateful events and social circumstances. Patients construct a renewed, viable and valued concept of self, as well
as a sense of coherence, stability and ontological security (Bury, 2001; Lawton, 2003) through narrative reconstruction. In her seminal work, Rajaram (1997) employed the concept of narrative reconstruction capturing the perspectives of carers of T2D patients who were insulin dependent. Rajaram (1997: 293) concluded that:

“Chronic illness is more than just the functional adaptation to the physical demands of the illness. It is the expression of a person's self-worth through bodily conduct in day-to-day life. 'The body is not merely the location of the disease, but is that through which one continues to apprehend the world and oneself in it' [...] While managing the illness, sufferers strive to project an image that is acceptable within socially and ideologically defined standards of moral virtue...”

It is further argued that such lay understandings can be arranged and edited, and the general importance of different factors inflated and deflated within the patients’ understanding and throughout their illness career (Lawton et al., 2003, 2008). These understandings affect the individuals’ practical coping strategies, ways of dealing with affective aspects of living with chronic illness, and finding a valuable identity in cultural repertoires (Bury, 2001). However, Rajaram (1997) concedes that the participants in the study were young, in a relatively stable phase of the illness, and relatively wealthy. The participants were purposively sampled to ensure they had experienced a recent ‘disruption’ in the flow of their lives. Although this homogeneity in sampling was appropriate to the aims of Rajaram’s study – there are issues of transferability outside of ‘narrative reconstitution’ studies, particularly comparison studies - as the approach brackets out how differing socio-contextual issues and stages in the illness may shape the resources and circumstances available for constructing narratives.

The seminal work of Hunt et al. (1998) explored the relationship between causative understandings and self-management activity in people with T2D. The study found that respondents were either self-active, other-active (others took care of treatment) or non-active. The study concluded that those who saw their illness as hereditary in their causative understanding, or as the result of ‘events’ were least likely to be self-active (Hunt et al., 1998). It was argued that
people’s understandings were also strongly influenced by their observations of the success or failure in self-treatment. People least likely to self-manage explained that there was little point in self-managing T2D as their condition was hereditary. The study classified people based on whether the person, somebody else or nobody took responsibility for care – regardless of: severity, what tasks were included in the regimen, and the social context of the individual’s care relationship. Thus, multiple factors could influence the conclusions. The study has also been criticised for not having a clear data analysis process (Campbell et al, 2003), and for considering self-care in a limited ‘individualised’ manner, as any activity performed by the person with T2D – thus negating how the condition is managed interdependently between people.

Further study has concurred that lay understanding of T2D is recursively shaped by day-to-day encounters, rather than solely through preceding beliefs. Lawton et al (2008a:47) explored patients’ illness-causation accounts longitudinally during a time of service delivery transformation for T2D in Scotland. The authors found that understanding of illness-causation was intertwined with experiences of health service delivery, i.e. “…[n]ot only did (different types of) health service delivery influence the ways in which patients thought about and self-managed their disease, over time patients’ disease perceptions also informed their expectations of, and preferences for, diabetes services” (Lawton et al., 2008a:47). Patients related the type of treatment and services they received to how seriously they should take the condition. This suggests that the tendency to bracket out clinical practices and recommended clinical behaviour as being at odds with lay understandings (discussed in section 1.2.3. below) – exaggerating the tension between clinical and lay approaches. Rather, in light of Lawton’s (2005, 2008a) studies, clinical approaches and patient understanding appear to be mutually informing, and cross pollinate. People living with T2D thus use clinical encounters to gauge and assess their self-management behaviour. In fact, in Lawton et al’s (2008a) study patients inflated or deflated aspects of their experiences in clinical encounters, and their causal accounts of T2D, to justify
certain treatment or lifestyle choices they made. Relationships with professionals are just one of many relationships that patients engage with. Thus, understanding adaption from the patient perspective involves understanding how a variety of social circumstances and social relations intertwine within the day-to-day management of T2D to shape the patients’ T2D management strategies.

In a review of lay experiences of health and illness, Lawton (2003) argues that the work of Bury and Williams (and wider work in lay understandings) has paved the way for exploring how the micro- and macro-contextual processes influence understandings of health and illness. Familial and interpersonal relations, for example, have shown to contribute to how chronic illness is managed and prioritised through interpersonal contexts (Campbell; 2003). For example, Gorawara-Bhat et al. (2008) explored how social comparisons play an important role in routinizing older patients’ T2D self-management. The study found that patients assessed their self-management relationally using their interpersonal relationships as a filter for assessing self-management- similar to Lawton et al (2008) in relation to health services. The study found that patients made ‘downward’ comparisons with individuals perceived as poorly managing T2D and that ‘upward’ comparisons were rarely made to those ‘managing T2D well’ - rather patients preferred to compare themselves with the ‘normal’ population. Patients often made social comparisons with the ‘normal’ population which lead them to adopt “normal” behaviours resulting in compromises in self-management routines, e.g. drinking alcohol. At the macro-level, categorical identities based on gender, class, and ethnicity are seen to pattern the personal meanings, constraints and opportunities experienced by people adapting T2D (Bissell et al., 2003). For example, Peel et al. (2005b) found that women with T2D saw diet as a personal concern, men tended to construct diet as a family matter. Lawton (2003) argues that later work in the experience of illness has demonstrated that: the ‘age and stage’ of onset and severity of the disease; changes in the society; and response to treatment across time are also important factors in
how people adapt to living with chronic illness - meaning that adaptation to chronic illness is not a singular adjustment period but a continuous, recursive adaptive process.

The on-going nature of adaption is captured in a study of advice that older adults living with T2D would offer newly diagnosed T2D patients, Hood et al. (2009) found several aspects to adapting to living with T2D: denial, acceptance of the condition, shock at the thought of insulin initiation, a need for moderation, and fighting for control over the illness. However, these categories are overarching themes, and Hood et al (2009) offers little explanation for any of the variations in the perceptions of those interviewed. Moser et al (2008) look at adaption to T2D independent of the personal meanings attached to the illness, by looking at commonalities in the adaption process. The study found three kinds of self-management processes – daily, off-course and preventative. The processes for self-managing in a ‘daily’ manner was accepting T2D, becoming aware of its ramifications, and acting in a routine manner. The ‘off-course’ process of managing T2D was a process of gaining awareness but spending time deliberating and evaluating; whereas in the ‘preventative’ process people became aware, learnt and acted on their knowledge. One strength of Moser et al’s (2008) study is that adaption processes are common throughout their sample, and are reported independently by respondents as recurring across the course of the illness. Moser et al’s (2008) study was able to suggest that patients act purposively and with autonomy, but there is commonality in the processes of adapting to T2D that repeat throughout the career of the illness. The authors note that their findings are limited by the potential bias that healthcare professionals chose the participants who took part in the study (selection bias), and that the study is limited in terms of representation, as no participants had suffered any complications. This means that these aspects of adaption reported may not apply as severity of the condition increases.

In overview, looking at adaption as a topic, we can see that some commentators frame adaption as a way people living with T2D manage the disruption that diagnosis creates, or as a means of creating continuity to the course of their lives. In the latter narrative-based approaches, people
living with T2D are seen to explain the impact of the condition as a process of rebuilding their personal and social standing, as well as adjusting their understanding to accommodate valorised social roles. However, these studies frequently employ homogenous samples (e.g. Hörnsten et al., 2004; Rajaram, 1997) – meaning adaption is seen as a linear process based on personal experience, so little is known about how different social contexts and different routes to diagnosis may contribute to adapting to living with T2D. Another aspect of adaption is the causative understandings of T2D that people adopt which have been shown to both shape and inform their perceptions of T2D; how they self-manage; and their expectations of support from family, healthcare professionals and services. Although the work of Hunt et al. (1998) suggests these causative understandings are long-term, fixed and global, Lawton et al (2008) found that causative understandings change over time (and are used by people living with T2D (like narratives) to justify and explain choices, preferences and so forth). Similarly, studies such as Lawton et al (2008a) and Gorawara-Bhat et al. (2008) have explored how people adapting to living with T2D use clinical and social encounters to gauge how well they are self-managing – suggesting day-to-day engagement with managing T2D and social comparisons inform perceptions in a recursive manner, and hence perceptions are seen to change over time and with circumstance. Other studies looking at recursive management of T2D explore commonalities in the experiences of adaption in order to highlight different processes of adaption rooted in people’s attempts to integrate the ramifications of T2D into day-to-day life – rather than exploring how people’s social roles and sense of self are renegotiated. However, studies looking at causative understandings, social comparison and (to some degree) day-to-day recursive responses tend to look at people with asymptomatic or non-severe T2D, without considering how factors such as progression and severity of the illness inform adaption.
1.2.3. Patients’ perspectives, understanding and experiences of managing T2D in a day-to-day context

Studies have shown that a multitude of psychosocial barriers exist for people living with T2D in performing clinically recommended behaviours and self-management. Secondary research (Nam et al., 2011) has found that barriers to managing T2D are explored in a numerous studies in multiple ways. One common method of measuring barriers to T2D management is the use of measures of diabetes-knowledge and attitudes to highlight their relationship with the clinically recommended behaviours (e.g. Anderson et al, 1990; Farmer et al., 2006; Davis et al., 2006). One criticism of these types of studies is the tendency to place the ‘normalisation’ of blood glucose as a central construct of the lived experience of illness, rather than understanding how the focus on normo-glycaemic levels itself creates barriers to self-management (Hunt and Arar, 2001). It is important to understand what factors mediate and moderate successful and unsuccessful management of chronic illness (Lawton, 2003). In many instances these studies of barriers and enablers highlight singular- and multi-factorial associations between patient characteristics and clinical measurements in a manner that suggests causal relationships. However, recent studies emphasising empowerment approaches have reduced this emphasis through introduction of measurements such as the quality of life and wellbeing as indicators of successful management (e.g. Tang et al., 2008). However, Nam et al. (2011) highlight that better understanding of the relationships between the multi-factorial barriers and enablers to T2D management as well as the mechanisms by which they mediate and moderate T2D management is required. In particular, how these mechanisms influence patients’ perceptions of living with T2D - which in turn, influence their health outcomes. The literature presented here sought to explore approaches attempting to gain an understanding of people’s T2D management in terms of their “...own logic, knowledge and beliefs which are grounded in the context of people’s daily lives...” (Williams, 1993:580).
Day-to-day management of T2D: Self-management as capacity for purposive and strategic management

The bulk of the work looking at the ‘day-to-day’ strategies people adopt to manage T2D are explored from the perspective of the patient (Nam, 2011). Kelleher’s (1998) seminal work on managing diabetes suggested that maintaining a ‘normal’ life was a key concern for people managing diabetes. A central construct of the study was exploring the ways people managed their illness to minimise disruption to their lives, showing how respondents’ managed ways the condition “impinged” on their day-to-day lives. The study found three main styles in which people managed diabetes: Copers who ‘strategically managed’ their illness by pre-emptively adjusting diabetes-related activities - such as timings of food to reduce ‘impingement’. Normalisers organised their daily routines and activities around their symptoms and care responsibilities, and hence were seen as complying to advice rather than ‘taking charge’ of the condition. The final sub-group were worriers/agonisers who tended to report being unwell, and having poor control over their condition leading to heightened anxiety. Kelleher (ibid.), reflects thinking at the time around ‘adherence’, hence, the study attempts to report the phenomenological experience of ‘non-adherence’ in a sympathetic manner. Participants’ responses are framed and weighted towards the assumption that people wished to achieve a way of life as ‘normal’ as possible within their social context, with deviations from this representing existential insecurities. This historical dating aside, a key problem with the analysis is that the categories were fixed and intransigent so respondents weren’t seen to move between categories over time (Campbell et al., 2003).

Similar to Kelleher, Maclean’s (1991) seminal work explored the factors that people living with diabetes had for ‘adhering’ or ‘not adhering’ to self-management dietary advice. The research also
found that, with experience, respondents were able to use their knowledge and awareness of changes in their body to inform management of diabetes, as opposed to more didactic information. Maclean also charted further factors found to influence patients’ responses to dietary requirements and their self-care. These being:

- Individual factors: Food history, coping skills, character traits, and gender.
- Diabetes factors: Severity, duration, experience and threat of complications
- Contextual factors: Family support, peer support, professional support, social norms, access and availability of self-monitoring equipment, and occupation.

Maclean developed a continuum of dietary-management styles ranging from: those who followed a strict diet plan; those who introduced a moderate to high degree of flexibility; to those who never, or rarely, adhered to dietary advice. It was noted that respondents’ views consistently reflected an inherent tension with regards to following dietary measures. This tension related to conflicts between the benefits for biological health (usually expressed as a bio-medical measure or increasing longer life expectancy) and feelings of well-being (a subjective sense of normalization, self-esteem and belonging through social integration). The underlying principle Maclean formulated was that where the pursuit of biological health did not compromise well-being, adherence was seen by respondents as less problematic. However, when the pursuit of health conflicted with well-being - individuals became more flexible with their care in order to minimize the perceived restrictions on well-being. This suggests that the respondents had developed underlying perceptual schema relating to how to manage their condition, based on balancing how recommended self-management practices conflicted with participating in everyday life.

This sub-theme of ‘restrictions’ that T2D self-management places on day-to-day living is a key premise of numerous studies (e.g. Collins, et al., 2009 and Ockleford et al., 2007) and the process of balancing clinical concerns against well-being concerns has been a consistent finding in T2D-
related patient experience research (Campbell et al., 2003). Brewer-Lowry et al. (2010) sought to explore the perceptual differences between those who did and did not meet clinically recommended behaviours. The study found that those who met clinical targets operationalised their self-management tasks in concrete terms and specific terms, as opposed to less structured descriptions given by those who did not meet clinical targets. This concept of an ability to *purposively and strategically respond to T2D* as a mediator of T2D self-management is a clear sub-theme in the literature on day-to-day management. In this seminal piece of research, O’Connor et al. (1997) conducted focus groups and one-to-one interviews with 34 people attending a diabetes education programme, in the United States of America. The researchers added a longitudinal element to their study which sought to explore how patients viewed their diabetes, their self-care and relationships with health care providers; and how these interrelated elements changed over time. Respondents were later interviewed again in a six month follow up to the educational intervention. The study set a baseline in the first instance by measuring blood glucose level following the structured education course, then again in the second tranche of interviewing. A typology was developed by comparing the views of those whose blood glucose levels had decreased by 20 per cent from their original baseline (called positive responders), and negative responders whose blood glucose levels had increased by 20 per cent or more over the six month interval. O’Connor et al. (1997) argue that there was a bifurcation of understanding, attitude and opinion between each group. Positive and negative responders differed: a) in their views and approach of diabetes, i.e. seriousness, b) how they integrated diabetes care tasks into their day to day lives, c) in ‘conversion experiences’ of becoming much more aware of the import of diabetes to their health, and d) in their views of their medical care providers. There was a link between lay understandings and physiological outcomes – with another salient feature being the capacity to manage T2D self-management tasks *strategically* (Campbell et al, 2003).
One strength of the O’Connor (1997) study would appear to be the use of an objective measure to produce categorisation, rather than the overarching categories emerging from commonalities or themes in the qualitative data. However, important effects are precluded from the baseline set, i.e. severity of illness, time since diagnosis/onset and other social factors (such as education and healthcare access), by circumscribing all contributory factors to the short temporal effect of physiological changes over the six months of the study. The subsequent dichotomy of positive and negative responders produces a thematic framework where the researcher is looking for what one group did ‘well’, in contrast to what the other group didn’t do well.

More recent work has continued to develop typologies based on the degree of purposive action undertaken by the individual with T2D. Collins, et al. (2009) explored perceptions of self-care coping strategies by people living with T2D according to self-care health value (the value the patient placed on their diabetes self-care in relation to their health); self-care responsibility (how self-care tasks were divided between self and others), and how the individual planned for, monitored and responded to the necessities of self-care. Three self-management types were identified:

- ‘Proactive managers’ who were self-directed, valued improving long-term health through self-care, and could independently maintain metabolic control through planning.
- ‘Passive followers’ followed their prescribed self-care regime and valued it, but did not react pre-emptively or autonomously to make changes to metabolic control; and
- "Nonconformist" patients who do not follow recommended self-care practices (ibid.).

The use of maximum variation sampling to recruit participants is a strength in this study– as patients in various stages of the illness and different treatment regimens were sampled. However, the self-management types were ‘ideal types’ grouped from patient responses (Collins, et al., 2009). Hence, personal and socio-demographic characteristics used to sample respondents were
never explored in relation to the typology of self-management developed. This means it is impossible to tell if different socio-demographic and T2D-related characteristics mediated or moderated orientation towards self-management ‘types’, rather self-management ‘types’ are seen to stem from the individual’s capacity for purposive action.

**Day-to-day management of T2D: Self-management, barriers and enablers**

Thus far, we can see studies have focussed on codifying and categorising behaviours based on how people normalise the management of the day-to-day restrictions of T2D, and how purposively or strategically people living with T2D manage these restrictions. Equally studies have looked at patients’ perspectives of T2D self-management to explore *barriers and enablers* experienced in the day-to-day aspects of the T2D self-management regimen – with some such as Maclean (1991) fusing both elements together. Exploration of barriers and enablers to T2D management are usually conjoined with suggestions of how to support patients to self-manage. Hayes et al (2006) explored the task of medicine management from the patient perspective, and found three main issues:

1) The inconvenience that administration of T2D treatments had on patients’ lives,

2) Patients’ desire to avoid injections and insulin therapy, and

3) The physical and emotional side effects of T2D medications.
Conversely, Morris et al. (2005) in a longitudinal study found that people who made the transition to insulin injections were initially shocked and reticent, but later grew to accept insulin injections – many finding it empowering to be able to control their treatment. The study concludes that healthcare professionals, by not addressing patients’ initial fears create barriers of resistance to adopting insulin.

The adoption of exercise and dietary control has also been found to be restrictive for people living with T2D (Fagerli, 2007; Casey et al., 2007; Wycherly et al., 2012) and on the diets of the wider family (Wellard et al., 2008). Casey et al. (2010) found that patients preferred structured support with exercising, in this case an educational programme, but tended to drift away from regular exercise when required to maintain the exercise regime under their own volition. They found that those living with co-morbidities were most likely to be ‘derailed’ from maintaining regular exercise following structured education. Wycherly et al. (2012) found that maintenance of dietary recommendations and regular exercise was not wholly an issue of motivation (as per Minet et al., 2011), but rather educational programmes offered free access to exercise and support on dietary change. Hence, people living with T2D who engage with structured education, experience financial and access barriers to the continuation of exercise and dietary practices when structured education programmes end. However, Malpass et al. (2009) found that exercise was found to frequently act as a ‘gateway-behaviour’ to wider self-management behaviour. One criticism that can be levelled at these studies looking at barriers and enablers is that these studies identify barriers and enablers with little regard for why different people experience similar aspects of self-management as having different costs or benefits – e.g. why do some people find exercise enabling whilst others find it restrictive? Differences are usually related to the competing demands and pressures faced by people living with T2D (Casey et al., 2010 & Hayes et al., 2006), or the activity having immediate benefits (Malpass, 2009). However, many studies point to the role of healthcare professionals (Fagerli et al, 2007; Morris et al., 2005). Some studies suggest that
factors relating to socio-contextual issues such as social support and income are influential (Wellard et al., 2008; Wycherly et al., 2012). However, these latter studies offer very little in terms of the generative mechanisms by which people are orientated to different self-management behaviours by socio-contextual factors.

**Self-management and health information**

These aforementioned studies on barriers and enablers to self-management activities frequently suggest it is important to understand how people living with T2D understand, and use, health information to address the burden of care they experience in self-management – and how accessible and useful the information provided is. There is some evidence for an association between health literacy and glycaemic outcomes with better outcomes for those most able to understand and use the information that they are given (Powell et al. 2007; Osborn, et al. 2010). Research has shown a person’s perception of health information is mediated by how appropriate the information is perceived to be to the concerns of the person living with T2D, with people tending to seek information that reflects their current needs (Onwudine et al. 2011). There is also evidence of variation in how actively people living with T2D seek information (Longo et al. 2010). Powell et al. (2007) found an association between poor glycaemic control and low health literacy, but also found that this relationship did not affect the individual’s health intentions or willingness to self-manage. This suggests a range of mediating factors, which might affect the ability of the person living with T2D to apply health information for managing diabetes. Studies relating to the application of health information have found that information is acted on and enhanced where the individual is able to draw on social support (Osborn et al. 2010) and healthcare professionals to interpret more complex information (Longo et al. 2010). Key factors found to mitigate the ability to act on T2D-related information include poor general literacy (Longo et al. 2010; Wallace et al., 2010); lack of awareness of target blood glucose and blood pressure management and finding diabetes-related health information confusing (Onwudine et al.
2011). These findings suggest that there may be problems with information provision over two levels; firstly, with appropriateness of the information per se; and secondly with the perceived lack of healthcare professional support in helping the patient interpret the health information or to address patient concerns early (Morris et al., 2005). Related to this, where the quality of healthcare professional communication is perceived to be poor by the patient, this has also been found to impact negatively on the patients’ ability to acquire health literacy (Schillinger et al., 2004). This suggests that individualised health literacy and information-giving approaches may mask deeper issues with healthcare professionals’ attitudes and approaches, systemic and socio-contextual influences which shape the barriers patient patients experience in acquiring and applying health information.

*The negotiation of social, familial, interpersonal and healthcare professional roles in T2D self-management*

A tranche of studies expand the notion of ‘people living with diabetes’ beyond purposive, self-directed action to demonstrate how management of T2D is influenced by social networks and health service-related factors (Gomersall et al., 2011). We have seen that Rajaram (1991) explored how families struggle to normalise diabetes within their lives, and maintain social acceptability – a process of adaption. Similarly, the work of Hunt et al. (1998) explored the relationship between personal understandings and self-care activity in people with diabetes and found that respondents were either self-active, other-active (others took care of treatment) or non-active. The study concluded that those who saw their illness as hereditary, or as the result of ‘events’ were least likely to be self-active. Other studies have shown that spousal support is a key element of successful T2D management (Trief et al, 2003; Beverly et al, 2007). Trief et al (2004) found that spousal support was a greater predictor of engagement with dietary control and exercise. However, Beverly et al (2007, 2008) found both congruence and differences in the perspectives of middle-aged people in couples living with T2D which influenced ways of managing the condition.
The study defined three key perspectives in couples – those who felt that T2D had highlighted how vulnerable they were at their time of life; those who described the burden the condition imposed; and those who saw T2D as a process of ‘getting by’ day-to-day. Beverly et al’s (2007) study is largely descriptive of participants’ perceptions. Parry et al. (2005) explored ‘cause and control’ beliefs related to T2D (discussed earlier in 1.2.2.), and found that these shape the way that people living with T2D divide tasks and responsibilities between themselves and others. They suggest that patients are required to grasp that both the cause and treatment outcomes of T2D are partly, but not wholly, within their control; and that the resulting understanding sometimes leads to inappropriate delegation of care and treatment responsibilities by the person living with T2D. This marries well with the earlier discussion that purposive action is shaped by people’s beliefs, as well as the day-to-day barriers people experience in relation to acting purposively. In combination, it appears that the ability to act purposively and causative accounts are related in some way, which supports Hunt et al’s (1998) findings that causative understandings influence how care tasks are delegated.

Studies have also investigated how perceptions of the consequences of diabetes influence the ways in which people plan, pre-empt and respond to their condition on a day-to-day basis. In a study exploring patients’ views of diabetes structured education, Ockleford et al (2007) found that acceptance of, or resistance to, the ‘diabetic identity’ alongside acceptance or resistance to the ‘consequences of diabetes’ informed the degree of purposive action a person committed to self-management. Four styles of self-management were identified: ‘resisters’, ‘identity resisters/consequence accepters’, ‘identity accepters/consequence resisters’ and ‘accepters’. It was found that these blends of accepting or resisting the diabetic identity in combination with the perceived consequences of T2D, informed the patient’s readiness to accept personal responsibility for self-management of diabetes (as well as their health education preferences). The study looks specifically at the newly-diagnosed, so there are limits to which the findings are applicable outside
this group. However, the study goes on to suggest that there are factors that precede and inform the individual’s capacity for purposive action, such as identity issues and how health concerns are formulated and perceived. For example the study notes briefly, that patients saw a moral element to their diagnosis (that their previous behaviour had contributed to T2D) with lapses in self-management being explained in a similar framework. Similarly, the participants reported factors which restricted, rewarded or diverted their capacity to achieve their intention and act purposively – that which Nuovo (2009) refers to as the ‘tyranny of the urgent’. This suggests that capacity for purposive action is preceded not just by people’s perceptions of their capacity to act, but also by experiences of barriers and enablers to action in their personal and social contexts.

Oftedal et al (2010) looked at patients’ experiences of support by healthcare professionals and concluded that motivating healthcare professionals can enable patients to self-manage. Patients reported that support should be underpinned by: 1) an empathetic approach; 2) practical advice and information; 3) involvement in decision-making; 4) accurate and individualized information; and 5) ongoing group-based support. Lawton et al. (2008a) have found that personal understanding of T2D is informed by health service delivery. The study (ibid.) showed that patients’ health beliefs were intertwined with the health care services they receive, for example, patients may feel that their illness is not as serious as it is managed by their General Practitioner (GP) rather than a Diabetologist. The study also found where T2D was asymptomatic, medical tests (and self-monitoring devices) often actualised the illness for patients through showing physical effects and potential consequences. Indeed, there are numerous studies showing improvements in patient self-management relating to which healthcare professional leads their care. Studies have shown that regular and sustained access to multi-disciplinary teams (Cuddihy et al., 2011;) Practice Nurses (Bartol,2012; Edwall et al., 2008; Kruger, 2008); Diabetes Specialist Nurses (Edwall et al, 2010; Moser et al., 2008); Community Health Workers (Otero-Sabogai et al., 2010) and tele-health interventions (Wu et al., 2010; Jennings et al., 2009) are all associated
with positive changes in self-management activity and outcomes. Other studies have also explored how experiences of T2D management can be also influenced by use of complementary medicine (Chang et al., 2012, 2011; Wang et al., 2011); improved through self-help and peer-support mechanisms (Lindenmeyer et al., 2010; Baksi, 2010; Rygg et al., 2010; Simmons et al., 2010).

One sub-theme within day-to-day management of T2D relates to patients’ experiences of clinical approaches, health services and organisational/systemic issues informing: 1) perceptions of T2D and its management, 2) How responsibilities for care and treatment are divided up, and 3) that these social relations inform self-management styles (Nam et al., 2011). This suggests that the management of T2D at the patient/provider interface involves delegating, or assigning roles and responsibilities which create different styles, methods and strategies of self (Nam et al., 2011). Many studies which emphasise how personal experiences of restrictions, maintaining ‘normality’, patients’ perceptions of barriers and ‘causative understanding’ inform self-management can be seen as overly individualised, and excluding a central causal factor - the context in which perception, experience and understanding is generated. Gomersall et al., (2011:14) note that in the T2D literature, self-management as a construct is frequently viewed as a means “…to regulate the self…”, as “…[t]here is a also moral dimension in that, after education and empowerment, should diabetes continue to be poorly managed, it is the individual patient who is construed as having failed”. The work of Lawton et al (2005; 2008) has shown that causative understandings, for example, occur as a recursive process that changed over time according to systemic factors – such as people adjusting their causative understandings according to the type of care they receive. The assumption of self-management as relating solely to an individual’s capacity for purposive action or as a matter of educating patients to overcome the personal barriers they experience, can be seen as reductionist; factors outside the individual, including facets of health care systems inform peoples’ perspectives, understanding and experiences of managing T2D in a day-to-day context (Newton and Asimakopoulou, 2008; Gomersall et al., 2011).
In terms of relationships with healthcare professionals, Campbell et al. (2003) note the distinction made in Kelleher and Maclean’s studies between health as a technical measurement, and well-being as a subjective experience. Studies in the doctor-patient relationship, particularly those focused on patient-centring, argue that better health and well-being can – or ought to - be attained in professional-patient encounters where information – both personal and technical - as well as treatment and option-deliberation are shared between participants (Morgan, 2003; Coulter; 2002). Hiscock et al. et al. (2002:25) note five main expectations patients had of their encounters:

- Friendly, warm and ‘equal’ approach to the patient;
- Willingness to understand the impact of diabetes
- ‘Partnership approach’ to treating the condition
- Willingness to make time to answer questions
- Proactive approach to making referrals to other healthcare professionals

Studies have also highlighted the role of communication between healthcare providers and those living with diabetes. Communication barriers have been found to be exacerbated with cultural and ethnic difference (Kokanovic and Manderson, 2007; Jones et al., 2008; Chlebowy et al, 2010; and Peek et al, 2010), and by gender (Matthews et al., 2009; Morris et al., 2005). In terms of empowerment a more central concern has developed around the doctor-patient relationship – that of the assumption of an equipoise relationship, i.e. the notion that all options available are made available to both parties in the ‘empowering’ medical encounter (Newton and Asimakopoulou, 2008). Paterson (2001) interviewed patients considered to be expert in managing diabetes. The authors defined ‘expert’ as: “…having the ability to make trustworthy decisions about self-management and maintain good overall glycaemic control…” (Paterson, 2001:576). A key finding was that patients reported that equipoise relationships could be undermined in two key ways: 1) Experiential knowledge was felt to be routinely discounted by professionals; 2) Professionals often failed to provide the resources necessary for people to make informed decisions. Similarly,
the work of Corser et al. (2010) highlights the frustration patients feel when managing the T2D using shared decision-making - when one decision-maker made decisions on managing T2D daily basis in the real world, whilst the other made decisions infrequently, from a doctor’s chair. However, what is lacking in studies of patients’ experiences of encounters with healthcare professionals is that the restraints working on the professional viewpoints are rarely captured. Studies of patients’ experiences of healthcare professionals’ contributions to self-management tend to lead to a ‘patient-as-good’ and ‘healthcare-professional-as-bad’ outcome due to one-sided reporting and analysis. It has been noted that different types of provision improve patient experience and health outcomes (Lawton et al., 2005; 2008). However, studies such as Corser et al’s (2010) and Paterson’s (2001) report patient experiences solely, with little consideration of the perceptions, understanding and experiences of healthcare professionals. It is ironic that in attempting to move away from individualised, patient-blaming frameworks involving the exploration of patient experiences of healthcare, much of the literature has moved to ‘professional-blaming’- as opposed to relational models looking at how patient and professional perspectives can mutually inform one another.

The role of systemic factors in T2D self-management

Alazri et al. (2006) looked at the role of wider health system factors (such as service organisation and delivery) have on patient management of T2D. The study used focus groups to explore how people living with T2D valued continuity of care in their relationships with healthcare professionals. Patients reported valuing three types of continuity:

- Relational continuity – care from the same health professional;
- Cross-boundary (team) continuity – effective transition and good communication between services;
- Informational continuity – where information about the patient followed the patient during cross-boundary transfers.

Patients rarely reported experiencing these types of continuity. Alazri et al’s (2006) study suggests a greater role for systemic factors, such as service organisation, in shaping patients’ experiences and expectations of services, and informing their capacity to self-management. Wellard et al. (2008) showed that systemic factors such as long waiting times and lack of appointments influenced patients’ self-management decisions. Mol (2008) explored T2D patients’ experiences of clinical encounters as ‘social practices’ within healthcare systems. The central argument of her work is that applications of shared-decision making in healthcare settings have moved encounters away from ‘a logic of care’ - which supported practices that promoted engagement in the day-to-day world, towards ‘a logic of choice’. The ‘logic of choice’ is seen to offer patients option arrays which they must choose, and having chosen, they are responsible for these choices as private concerns. This promotion of choice is seen by Mol to be at odds with the intricacies of managing T2D and responding to the patient experience, as Mol (2008:10) succinctly states: “As if it were a magic wand, the term choice has ended all discussion”. Mol’s (2008) findings align with Gomersall et al’s (2011) assertion of a tendency to individualise patient experiences of self-management as personal barriers to self-management, rather than systemic and socio-contextual barriers. Another systemic factor raising concern about shared-decision making models relates to the additional training of professionals in the empowerment approach. Although health initiatives in the UK, such as the NSF or Diabetes Education and Self-Nanagement for Ongoing and Newly Diagnosed (DESMOND) contain programmes designed to ameliorate gaps in professional capacity (Varty and Varty, 2006) – it is assumed that professionals will naturally adopt the paradigm and that patients will accept the change in their healthcare provider’s approach. There is little evidence demonstrating whether appropriate constructs exist to measure communication processes and outcomes in the empowerment approach in relation to professional
input and patient outcomes (Asimakopoulou, 2007). Hence, although the actions of healthcare professionals can and do influence patient perceptions, understanding and experiences of managing T2D, there are preceding factors at the systemic level that shape the context of the healthcare professional and patient perceptions.

**T2D-related factors and their influence on self-management**

One largely overlooked area of research into patient experiences of T2D is how illness itself creates physical changes in the body which impact on experiences of people living with T2D. One important aspect of Murphy and Kinmouth’s seminal study is the notion of ‘embodiment’ where it is argued that a key catalyst to self-care behaviour is the ability of respondents to observe and respond to their own bodies. The authors noted patients judge the utility of medical advice, by interpreting the efficacy of the advice through impact on the physical manifestations of T2D. O’Connor (1997) found that tangible experiences of symptoms, and complications, as well as clinical evidence actualised the presence of diabetes in the body for patients – particularly the asymptomatic and newly diagnosed. O’Connor also found that tangible experiences of the impact of diabetes are a prerequisite in learning to ‘strategically manage’ the condition, and frequently this only came with time (O’Connor, 1997). Hunt et al. (1998) found that people’s willingness to self-manage was strongly influenced by their observations of the success or failure of performing recommended self-management practices. The progression of T2D is such that 60% of people living with diabetes will eventually require insulin treatment, which is frequently interpreted by these people as a form of personal failure or a fated punishment of poor management (Nam et al., 2011), but can also be empowering as previously stated (Morris et al., 2005). Heisler et al. (2005) found that T2D patients who knew their HbA1c levels reported better understanding of diabetes self-management than those who did not know their level. Song and Lipman (2008) have also noted that people living with diabetes are required to be aware of a range of T2D manifestations, and be able to interpret and respond to them. Song and Lipman (2008) further argue that this
process is largely influenced by subjective experiences and socio-contextual factors – hence physical manifestations are interpreted and understood accordingly through the social context, e.g. dizziness from high blood sugar becomes a problem if it begins to affect the patients’ capacity to work. Both Maclean’s (1991) and Lawton’s (2003) studies contained a longitudinal element, showing how meanings and understanding changed over time, hence, perception is not fixed but adapts with physiological, individual and contextual changes.

The literature above suggests physical changes in the body can impact on perceptions and experiences by people living with T2D. People living with T2D also manage multiple conditions and illnesses (Nam et al., 2011). Numerous studies of patient experiences (Bayliss et al., 2003; Jerant et al., 2005 and Visram et al., 2008) have found that co-morbidities are a major barrier to self-care activities in T2D. People with T2D can be managing multiple conditions which pre-existed their diabetes diagnosis, e.g. Asthma, HIV or Lupus. They can also be managing conditions resulting from living with T2D, these can be: micro-vascular – e.g. diabetic neuropathy or retinopathy; or micro-vascular – e.g. cardiovascular disease, cerebro-vascular disease and coronary artery disease. Equally, co-morbidities can be any non-diabetes related acute illnesses or morbidities diagnosed following T2D diagnosis. Depression, for example is also linked to all of these aforementioned categories, and has been shown to alter perception of T2D self-management and is associated with increased morbidity, mortality and functional limitation – these physical outcomes (co-morbidities) are seen to have a bi-directional relationship with depression (Nam, 2011; Chao et al, 2005; Jennings et al., 2009). Managing co-morbidity is, for example, seen to impact positively on symptom interpretation. Beverly et al. (2011b) found that women living with T2D who developed myocardial infarction spotted the symptoms earlier as not their ‘typical’ T2D symptoms. Similarly, Kreyenbuhl et al. (2011) found that people managing mental illness were better able to control blood glucose than those without mental illness, this skill was advantage conferred from managing multiple conditions. However, Kerr et al. (2007) found that patients
with greater numbers of co-morbidities placed lower priority on managing T2D and had low diabetes self-management ability. Kerr et al. (2007) also found that only macro-vascular and non-diabetes-related co-morbidities were associated with de-prioritising self-management of T2D. Whereas living with higher numbers of micro-vascular, macro-vascular, and non-diabetes-related conditions were associated with poor self-management. Severity of macro-vascular conditions was negatively correlated with prioritising T2D self-management, i.e. the more severe the condition, the less the person self-managed. This suggests that managing T2D itself may not be the priority in patients’ perceptions where a range of co-morbidities exist. Although the realm of physical manifestations may impact in numerous ways on the perceptions of people living with T2D, it must be taken in the context of other illnesses. Although physical manifestations are an important influence on perception they are also interpreted through people’s subjective experiences, as well as systemic and socio-contextual conditions (Song and Lipman, 2008).

**Socio-contextual factors and their influence on self-management**

Far removed from exploring perceptions and understanding of the physical manifestations of T2D, studies have sought to identify socio-contextual factors that shape self-care practices and ‘adherence’ to T2D therapies (Brown et al., 2004). Maclean’s study (discussed above), for example, found people’s responses were influenced by individual factors such as character traits and gender; diabetes factors such as duration and severity of the condition; and contextual factors such as degree of family support available. Other studies have looked ethnic and cultural differences (e.g. Kokanovic and Manderson, and Peek et al, 2010) highlighting how culture influences a person’s perception of their illness. These range from exploring how ethnic and cultural difference shape: the patient-professional relationship (Peek et al, 2010; Jowsey et al, 2011); compliance with recommended clinical behaviours (Lawton et al., 2006b); and the unique lay understandings of T2D in different cultures (Lippa and Klein, 2008; Skelly et al; 2008). Elstad et al. (2008) used focus groups to explore patient perceptions of T2D in American Samoan
communities. The study found that 4 factors perceived to cause T2D-related stress could be divided into:

- Individual stressors – physical symptoms;
- Familial stressors – Lack of support at home;
- Environmental stressors – Changes in food sources and dietary practices as access to food has changed from a subsistence way of life to one of living and working in a cash economy;
- Cultural stressors – cultural stress was associated with adapting to a rapid cultural and economic change in their community.

Studies exploring patients’ experiences of self-management and wider structural and social-contextual factors frequently see culture as a confounding variable in health outcomes which are to a greater extent influenced by socio-economic factors. This is because cultural and ethnic minorities tend to be over-represented in poorer socio-economic groups which is a causal factor in poorer health (Brown et al., 2004; Fagerli et al., 2007). In a review of how socio-economic factors affect health in all types of diabetes, Brown et al (2004) argue that the mediators and moderators can be proximal in nature (factors such as health behaviours, access to care, and processes of care which influence health outcomes); and distal (factors which act through shaping the ability to engage with health behaviours, access to health, and care processes). The authors also argue that although factors such as age, ethnicity/culture and gender are important covariates that can independently shape health outcomes, they are secondary, or confounded by differences in socio-economic position. Although there is strong evidence for socio-economic position having a preceding influence on T2D health outcomes (Espelt et al., 2008; Gomersall et al., 2011), there are only a handful of studies looking at the lived experience on managing T2D on a low-income – mostly from the US (Cuesta-Briand et al, 2011; Beryl-Pilkington, 2010 and Savoca et al; 2004). In
general, these studies look at proximal factors – competing demands on patients’ time and resources and living as ‘uninsured patients’ – and how these issues could be addressed by policy and professional practice. These studies use homogenous samples to highlight individual behaviours and barriers which relate solely to people on a low income. More heterogeneous samples, including those on higher incomes, may give a clearer picture of how income contributes to successful management and/or better health outcomes, and a clearer picture of the role of income and wider socio-contextual issues in T2D self-management. One US study, by Figaro et al. (2009) found that perceptions of the ability to control the outcomes of diabetes were linked to socioeconomic position. Those in lower socio-economic groups were found to have lower expectations in the health outcomes associated with self-caring when compared to those in a higher socio-economic group who were more confident about their ability to perform self-care tasks to modify the course of the illness.

Looking at the key trends identified above in relation to patients’ experiences of T2D management, namely: competing demands of maintaining ‘wellbeing’ and health, managing restrictions and co-morbidity, the role of social support, ability to manage T2D purposively and strategically, as well as perceptions of causes, severity and consequences; it is clear these factors are rarely explored in the context of the key causal juncture of the socio-economic patterning of T2D. Hence, Gomersall et al. (2011:853) in a meta-synthesis of self-management studies in T2D conclude that:

“[S]elf-management was sometimes construed as a facet of individual agency and was accepted uncritically, placing accountability for health with patients themselves ... [A] satisfactory account of diabetes care would pay attention to the ‘inner’ world, while acknowledging the social and political conditions in which diabetes-related experiences unfold”.

In relation to ‘empowering’ patients, many of the studies discussed above suggest that understanding patient perspectives should inform ways of empowering patients to self-manage.
Commentators exploring theoretical aspects of the empowerment approach as applied in T2D (Asimakopoulou, 2008; Newton and Asimakopoulou, 2008; Redman, 2007) have concerns that the ‘distal’ moderators and mediators of T2D self-management (factors which act through shaping the ability to engage with health behaviours, access to health, and care processes), precede and shape not only proximal mediators and moderators (factors such as health behaviours, access to care, and processes of care) in terms of health outcomes, exacerbating the capacity of individuals to harness health services delivered in a patient-led, ‘empowered’ fashion. Redman (2007:246) for example, describes this concern with the uneven capacity to engage with the empowerment approach using the example of health education:

“The potential for widening the gap between the ‘haves’ and the ‘have nots’ in healthcare is very real, as the ‘have nots’ struggle with low literacy, the resulting inability to self-educate and lack of access to educational materials and teachers matched to their learning needs”.

Thus, it is important to understand the mechanisms by which socio-contextual factors shape patients’ day-to-day experiences of managing T2D, and how these fit with empowering models of healthcare targeted at individual behaviour.

1.2.4. **Summary of literature on patients' perspectives, understanding and experiences of T2D and its management**

Within the literature, emotional responses to diagnosis were found to be informed by routes to diagnosis, and the manner in which professionals deliver diagnosis. Studies explore the uncertainty following T2D diagnosis and how this informs the way people manage the condition. The study of T2D-diagnosis experiences is, however, characterised by homogenous sampling of the newly diagnosed which frequently negates the effect of progression and severity of T2D at the time of diagnosis. How people adapt to living with T2D yielded three key sub-themes. Narrative
approaches look at the meanings attached to the illness and how this influences the process of managing the illness. Partially related to meanings attached to illness, studies look at the causative and control understanding people have of T2D, and how this informs self-management. More recently, studies explored how people use clinical and social encounters to gauge how well they are self-managing. These approaches suggest that day-to-day engagement with managing T2D, causative understandings and social comparisons inform perceptions in a recursive manner - portraying adaption to T2D as an on-going, recursive process. However, studies looking at causative understandings, social comparison and day-to-day recursive responses tend to look at people with asymptomatic T2D, without considering how factors such as progression and severity of the illness inform perception, experience and understanding. Recursive models of adaption do highlight a role for socio-contextual and systemic issues to influence T2D self-management through direct experience – rather than as one element within a narrative.

In the broad area of literature relating to patients’ perspectives, understanding and experiences of managing T2D in a day-to-day context a range of themes (containing sub-themes) were found. Studies looking at self-management of T2D on a day-to-day basis have looked at the capacity of people living with T2D to manage the restrictions engendered in a purposive and strategic manner. One shortfall of these studies is that they frequently bracket out how social and systemic issues create barriers to purposive action. Other studies, however, have emphasised how restrictions are barriers (personal, systemic and/or socio-contextual) to self-management are experienced by people living with T2D, and how aspects of the T2D regimen can sometimes be interpreted and employed in an enabling fashion by people living with T2D. These latter studies are criticised though for merely reporting barriers and enablers within the context of competing demands within the individual’s life, rather than related to socio-contextual patterning of barriers and enablers - although some studies do relate barriers and enablers to aspects of healthcare professionals’ attitudes, systemic and socio-contextual issues. Related to capacity for purposive
action and approaches looking at barriers and enablers to self-management are studies looking at use of health information. The majority of this work is framed with the health literacy model which is strongly orientated to the notion of information provision improving individual purposive capacity. Findings show problems with information provision over two levels: appropriateness of the information per se and with the perceived lack of HCP support in helping the patient interpret the health information. Other commentators argue that individualised health literacy and information-giving approaches may mask deeper issues with healthcare professionals’ attitudes, and systemic and socio-contextual influences which shape patients’ abilities to acquire and apply health information.

In contrast to approaches focusing on the individual, studies have looked at the role of familial, interpersonal, healthcare professional and wider social relations in T2D self-management. Factors such as social support networks and willingness to adopt the ‘diabetic identity’ are seen to shape the delegation of care between self and others. Differences in understanding between healthcare professionals and patients are also seen to influence role adoption and role expectations which shape self-management behaviour – as are the type of healthcare professionals that patients are able to access. Patients frequently use healthcare professional interaction, as well as the status of the healthcare professional to assess the significance of their condition. Patient-provider relationships may be difficult to explore using solely patient perspectives. Studies at the systemic level which show that factors relating to the systemic level – such as continuity of care – influence the perceptions and expectations of people living with T2D. Research has also shown that the adoption of new paradigms informing healthcare delivery can influence patient-provider relationships, and ways of measuring the effectiveness of new approaches may be inadequate. Studies have also focused on exploring how changes in the body (embodiment), such as symptoms, complications and the presence of co-morbidity can influence patient perception of self-management. For example, patients may blame themselves for successes and failures in self-
management, or use embodied sensations as a gauge for the effectiveness of treatments. We have seen that much of the work discussed can be criticised for focusing on asymptomatic T2D. However, this focus on the physical realm has been criticised as studies rarely tease out how socio-contextual factors shape the subjective experiences of illness. The presence of antecedent and developed co-morbidity alongside T2D is also seen to influence the priority afforded to T2D self-management, as is the type and nature of co-morbidity.

It has been shown that culture is a well-researched area of T2D management particularly how causative understandings and cultural distance in patient-provider relationships shapes self-management behaviour. Conversely, secondary research suggests that the influence of culture and ethnicity may be explained by socio-economic, materialist explanations – as people from ethnic and cultural minority groups are disproportionately represented in lower income strata. Related to this, it has also been noted throughout the above discussion that socio-economic patterning of T2D is often neglected in the study of T2D self-management. Socio economic factors are frequently referred to obliquely as proximal through the notion of capacity for purposive action within the competing demands of T2D self-management. It is occasionally referred to as a distal factor (a factor which acts through shaping the ability to engage with health behaviours, access to health, and care processes, i.e. a barrier). Few examples of research exploring a link between these two types of factors were found in the literature search - i.e. how socio-economic factors shape barriers and enablers to self-management as well as expectations of and, hence, capacity for self-management. This is despite evidence that T2D health prevalence and self-management outcomes are strongly patterned by socio-economic differences.
1.3. **Healthcare professionals’ perspectives, understanding and experiences of T2D and its management**

This strand of the literature review yielded the smallest amount of literature. Three main sub-themes were identified:

a) Barriers and enablers to T2D management at the patient, provider, systemic and socio-contextual levels;

b) Healthcare professionals’ day-to-day perspectives, understanding and experiences of managing of T2D; and

c) The empowerment paradigm and T2D management;

This are discussed in turn below.

**Barriers and enablers to T2D management at the patient, provider, systemic and socio-contextual levels**

Brown et al’s (2002) conducted a seminal study investigating factors which facilitated and thwarted the ability of healthcare providers in implementing clinical guidelines about the management of T2D. Looking solely at healthcare providers’ (n=40) perceptions of the management of T2D using focus groups, the study found that there were barriers and facilitators of self-management at the systemic, provider and patient level. Barriers at the systemic level referred to the organisation of healthcare, such as types of services provided and remuneration. Patient barriers and facilitators were rooted in provider perceptions of patient ‘non-compliance’, mainly referring to the attitudinal and behavioural aspects of patient self-management. Provider barriers related to healthcare professionals’ inadequate knowledge and skill sets (e.g. keeping abreast of pharmacology) and frustration with systemic barriers – with training and information
technology reported as facilitators at the provider level. The study suggested that there was a degree of interaction between these factors, with for example, systemic factors (such as lack of time) impacting on provider factors (such as not being able to update skills).

Bhattacharrya et al. (2011) build on these categories adding that ‘environmental’ factors, relating to demographic and socio-economic factors outside the healthcare system interact with systemic, provider and patient factors in diabetes care. Bhattacharrya et al. used interviews and focus groups to define healthcare professionals’ perceptions of providing diabetes care in first nation, aboriginal communities in Canada. The patient, provider and systemic factors in this study were largely similar to Brown’s study. The study found that providers perceived that patient factors had the largest impact on T2D management, with provider factors having less impact, and systemic factors being seen as having very little impact on care. Environmental factors were seen largely as non-modifiable, and rarely prioritised as an area for action. However, community health representatives (from ‘first nation’ communities) and providers in isolated communities were less likely to report patient factors as a barrier to care, and more likely to report provider and systemic factors as having greatest impact on diabetes care. Bhattacharrya et al’s (2011) study argued that there was a strong tendency for ‘patient-blaming’ in professional approaches particularly where there is cultural and social distance from the patients served.

**Healthcare professionals’ day-to-day perspectives, understanding and experiences of managing of T2D**

Puder and Keller (2003) interviewed healthcare professionals about their attitudes to managing T2D and found that they considered T2D to be a non-serious illness. Similarly, an often cited study by Larme et al. (1998) looked at the attitudes of professionals in primary care towards treating T2D. The study found healthcare providers considered T2D difficult to treat, and questioned the efficacy of T2D treatments. The authors suggest that this may exacerbate patients’
frustrations with self-managing T2D, meaning the joint perception that control of the illness is outside patient and healthcare professional control is a barrier to empowering the patient. Larme et al. (1998) did not interview patients in their study, so the assertion of cross-pollination of frustrations between patients and providers is conjecture. Systemic issues relating to continuity of care have been found to influence healthcare professionals’ views of T2D with a number of studies having shown that improving quality of care through integrated care approaches (Grimmer-Somers et al., 2008; Nuovo, 2009; Brez et al, 2009) can address many of the failings in information transfer and referral which providers perceive as thwarting continuity of care. These aforementioned studies designed to improve continuity of care do not track the impact of the interventions on patients, rather providers’ opinions of improvements are usually reported as a proxy for patient opinion. It has been found that incorporating patient perspectives in the training and education of healthcare professionals’ improves healthcare professionals’ perceptions and attitudes towards patients (Holmstrom et al., 2004).

**The empowerment paradigm and T2D management**

Studies based on healthcare professional perceptions of T2D management have explored professional perspectives of working in systems where empowerment is the key philosophy underpinning practice. Adolfsson et al. (2004) used focus groups to interview nurses and physicians to explore healthcare professionals’ perspectives of the barriers and facilitators encountered in implementing empowerment group education for people living with T2D. The study found that healthcare professionals felt conflicted as they felt it was easy for them to ‘slip back’ into practising in a traditional, paternalistic style. The healthcare professionals in Adolfsson’s study found their roles had changed from being an expert – to one of being a facilitator. Empowerment was seen as an aspiration or ideal way of working, but the realities of working life such as lack of time and resources as well as pressure to meet clinical aims (i.e. provider and systemic factors), created barriers to adopting the approach. Wens et al (2005) found
that GPs tend to resort to directive, paternalistic approaches when they were frustrated with their patients’ non-compliance with T2D self-management recommendations, which GPs saw as having a clear evidence base.

Luftey’s (2005) ethnographic work on healthcare professionals’ management of T2D in the US highlighted professionals as autonomous social actors. This argument purports that providers combined their knowledge of patients’ experiences with their medical knowledge to effect change in patients. Luftey (2005:421) describes how professionals adopt the positions of

“educators, detectives, negotiators, salesmen, cheerleaders and policemen [to] tailor their actions to specific patients in order to maximise their adherence to treatment regimens”.

Healthcare professionals adopt multiple roles from authoritarian to facilitating to empowering in order to reflect what they feel best suits the patients’ needs. Professional and patient roles are seen as relational, developing in tandem with one another in mutually informing ways. However, Luftey’s study took place in a Diabetes Education Centre where this kind of customised care was allowed for. Hence, Luftey (2005:443) contends that the relationship between patient adherence and professional roles

“...may ultimately be not only about individual physicians enacting stances and practices customised to individual patients, but also the organisational and ecological environments in which they come together”.

This suggests that systemic and socio-contextual issues which impact on patients and providers may inform and influence the barriers and opportunities experienced by both professionals and patients.
Using semi-structured qualitative interviews, Asimakopoulou et al. (2012) and Scambler et al. (2012) explored what healthcare professionals working with T2D patients understood by the term ‘empowerment’, their attitudes towards it and whether they believed they practised in ways consistent with empowerment principles. The second part of the study looked at barriers and facilitators healthcare professionals experienced in achieving empowerment in patient care (Scambler et al., 2012). The two-part study found that healthcare professionals had various interpretations of what empowerment meant which in turn informed their practices. Professionals frequently described empowerment as a process of encouraging choice, however, this ranged from leading patients to predefined options to suggesting that patients also have the right to not choose. Anderson et al. (2006) suggest that people are making an informed choice by not choosing, and professionals should encourage ‘ownership’ of the illness. This premise offers an excellent example to Mol’s (2008) notion of the ‘logic of choice’ superseding the ‘logic of care’. However, other commentators (Asimakopoulou et al, 2007, Newton and Asimakopoulou, 2008) argue that Anderson et al’s (2006) approach is reductionist and brackets out the social, systemic, provider and personal barriers people experience which can thwart their capacity to take on the clinically-driven options offered to them, and which – others have argued – also present serious ethical issues (Redman, 2007).

The healthcare professionals interviewed in Asimakopoulou et al’s (2012) study reported that clinical targets were the best indicators of empowerment, with a few referring to quality of life as an important component. Patients were frequently labelled ‘un-empowerable’ by professionals if deemed not to be maintaining clinical recommendations, or choosing to not choose – they also reported that older people and people form minority ethnic groups were most likely candidates to be ‘un-empowerable’.

The second aspect of the study (Scambler et al., 2012) looking at barriers and enablers to empowerment did, however, find that empowerment offered professionals a means of controlling
resources through channelling resources to patients most in need – ‘selective empowerment’; as well as providing a new range of skills professionals could draw from. The healthcare professionals in the Scambler et al’s (2012) study reported systemic issues relating to limited resources, workforce issues such as resistance to empowerment by some professionals as well as poor organisation of health services. The study took place in a socially deprived area of the UK, so healthcare professionals in this study also reported socio-contextual such as finite resources for health, the disadvantages associated with the socio-demographic characteristics of the population they served, and the limitations of what was possible in the strictures of prevailing health policy. However, unlike the professionals in Bhattacharrya et al’s (2011) study who deemed socio-contextual issues as non-modifiable, the use of ‘selective empowerment’ by professionals in Scambler et al’s (2012) study suggests that some professionals acknowledged, and attempted to circumvent, the effects of systemic and socio-contextual issues which impacted on T2D management through modifying their practices. The study also hints at a relatively unexplored factor influencing perceptions of empowering T2D management – the natural biological progression of T2D. Healthcare professionals gave examples of patients who have poor clinical outcomes despite the patient being thoroughly empowered to deal with them - due to the stage the illness has reached.

In overview we can see that T2D-management by healthcare professionals occurs over various patient, provider and systemic levels which engender different barriers and enablers. Healthcare professionals face challenges in managing T2D on a day to day basis with communication with patients, and how systems healthcare delivery shape healthcare professional capacity to provide quality care. Finally, we can see that the shift to empowerment has engendered further barriers and facilitators which shape these aforementioned issues.
1.4. **Patients’ and healthcare professionals’ perspectives, understanding and experiences of T2D and its management**

Within this strand of the literature review, two main sub-themes were found:

a) Congruence and divergence in patients’ and healthcare professionals’ perspectives, understanding and experiences

b) Role expectations of patients and healthcare professionals

These are discussed further below.


**Congruence and Incongruence**

There is a small, but longstanding tradition of contrasting patient and healthcare professional perspectives on the management of Type 2 Diabetes (T2D). One seminal piece of research, Cohen et al (1994) contrasted the ‘explanatory models’ of diabetes that patients and practitioners brought to the clinical encounter. Cohen et al (ibid.) interviewed patients and professionals in a single health locale and contrasted their views on various aspects of diabetes care. The patient sample was homogenous and chosen to match the backgrounds of healthcare professionals. The study found that when discussing their understanding of various aspects of T2D - such as aetiology, patho-physiology and severity of the illness - patient and provider views were highly incongruent despite the commonality of social backgrounds. Patients’ accounts saw diabetes as ‘in the family’, explained diabetes as the ‘pancreas quitting’ and underplayed the seriousness of the illness; professionals relied on their clinical knowledge to discuss the clinical ramifications and serious nature of diabetes. Cohen et al (1994:65) did find strong agreement in patients’ and providers’ accounts in one area – the need for “tight control” of blood glucose levels. The study concluded that when describing aspects of diabetes treatment, practitioners and patients frequently referred to different interpretive domains. Practitioners discussed the impact of diabetes on the patient’s body in a physiological manner, whereas patients tended to discuss the impact of diabetes as day-to-day difficulties they experienced. Studies, subsequent to Cohen’s study, have also supported this premise of a divergent fit between patients’ and healthcare providers’ perspectives in a number of areas, such as: continuity of care (Casparie and van der Waal, 1995); barriers to exercise (Schultz et al., 2001); self-management of blood glucose levels (McIntosh et al., 2010); barriers to insulin injection therapy (Rubin et al. 2009) and treatment goals (D’eramo-Melkus and Demas, 1989).

Cohen et al’s findings have acted as a premise of many subsequent studies contrasting patient and provider perspectives of managing T2D (Pooley et al., 2001; Tang et al., 2008). Conversely, Hunt
and Arar (2001) have argued that this early work looking at patient and provider perspectives is primarily concerned with identifying factors that contribute to patient ‘non-compliance’. It is argued that studies set in this ‘non-adherence’ paradigm, like Cohen’s, are problematic as they tend to consider patient understanding as a point of departure from the provider perspective. Hence, clinically-informed, healthcare professional understanding in these studies is portrayed, unquestioningly, as a given – that the patient is required to accommodate. Hunt and Arar further argue that patients are frequently ascribed behavioural characteristics based on how they have accommodated the clinically informed expectations of health professionals. Hence, the ‘adherence’ approach is critiqued for unquestioningly reinforcing professional expectations and, likewise, shifting the burden for ‘adherence’ onto patients. At the same time, the everyday circumstances confronting patients and their concerns patients are seen either as something professionals should ‘work with’ to ensure compliance, and/or as behavioural or personality characteristics requiring modification. Hunt and Arar (2001) note that these ‘explanatory model’ approaches to contrasting patient and provider views had originally called for more scrutiny of both professional and patient perspectives (see Kleinman, 1976). However, Hunt and Arar (2001:350) suggest that in application the approach had become

‘... a means for explicating patient perspectives in terms that are almost diagnostic.’

Hunt and Arar’s (2001) own work sought to expand the analytical framework for contrasting patient and provider ‘views’ of managing T2D. Therefore, to avoid a framework which placed the burden of responsibility for ‘adherence’ on patients yet allowed for scrutiny of professional perspectives – the authors looked at the interplay between the goals, strategies and evaluation criteria that patients and healthcare professionals employed in the process of managing T2D. Using a qualitative approach, Hunt and Arar sampled low-income, Mexican people living with diabetes in the USA and contrasted the perceptions within this group, to those of the health professionals working in the public clinics and health centres serving this population. Unlike
Cohen et al’s study, Hunt and Arar did not circumscribe predefined perceptual areas such as ‘symptom occurrence’ and ‘pathophysiology’ a priori, but rather explored the ways patients and professionals defined, engaged with and evaluated the process of managing T2D. The study found that providers’ accounts of managing T2D were primarily grounded in the clinical context and adherence to clinically-recommended behaviours. Patient concerns were only considered relevant insofar as they impacted on clinical recommendations. Hence, “...failed treatment is attributed to lack of patient cooperation, either wilful or arising from ignorance” (Hunt and Arar, 2001:361). In short, promoting successful management was seen by professionals as a case of educating or motivating the patient.

The study found that patients’ experiences of self-managing diabetes were inseparable from the circumstances and competing demands they encountered in day-to-day life (Hunt and Arar, 2001) - providing numerous examples of how the majority of patients interviewed (all but one) were well-informed and motivated to manage their condition. Hence, Hunt and Arar (2001:361) concluded that patients’ capacities to manage were not thwarted by application in their everyday lives or motivational issues but by

“... the impracticality of the [clinical] recommendations, especially for people with limited economic or social power...”.

The tendency of providers to focus on educating or motivating patients is, thus, misplaced as patients

“...are involved in a continual process of balancing their treatment behaviours against the multiple competing nonmedical factors that they must manage in their lives, such as demands of family and jobs and meeting economic obligations...” (Hunt and Arar, 2001:362).
We can see that Cohen et al’s study has ascribed a priori, deductive categories, through a set annotated areas of analysis imposed on the illness process – e.g. aetiology, treatment, symptom onset – before tallying each group’s descriptors of these areas. This is partially explained by the researchers’ aim of exploring reasons for ‘non-adherence’ to clinically recommended behaviours. Conversely, Hunt and Arar’s study is designed to explore and analyse professional and patient experiences and perspectives of the process of managing diabetes in an inductive fashion – looking at how preceding engagement with the condition, role enactment and related viewpoint have informed patient and provider understanding. Both studies however, reach similar conclusions, albeit with different explanatory factors. Both, for example, found that professionals tended to assess success and failure through clinical recommendations, and that patients and professionals agreed on the need for tight control of blood glucose levels. However, this similarity in findings is fleeting in both approach and outcome. Hunt and Arar suggest that when the notions of ‘control’ - common to both provider and patient perspectives - are analysed in terms of each groups’ goals, strategies or evaluative criteria, they are semantically distinct. Patients measured ‘control’ by how they felt physically, and the degree to which recommended targets and associated behaviours could be practically integrated into everyday life. Hunt and Arar’s approach places professionals and patients on an equal analytical footing by focussing on how both groups formulate goals, strategies and evaluation criteria in the common process of managing diabetes. The authors argue that Cohen et al’s study places clinical norms as a baseline for patient behaviour. This is a contradictory finding to Cohen et al’s assertion that patients aspired to the notion of controlled, clinically recommended blood sugar levels (and identified with professional expectations), but that day-to-day life tended to lead their intentions astray. Rather, in Hunt and Arar’s analysis, patients, day-to-day competing demands, experiences and circumstances were reported as the essential building blocks of the goals, strategies and evaluative criteria of self-
caring. In fact, those patients in Hunt and Arar’s study who achieved ‘control’ aligned with clinical recommendations, were often frustrated by the lack of progress or influence this type of control afforded them.

The different conceptual domains by which patients and health professionals – as well as the degrees of congruence and divergence between them – continue to be explored in subsequent studies in the area (e.g. Woodcock and Kinmouth, 2001; Brown et al, 2002; Pooley et al., 2001; Schultz, 2001; Tang et al., 2007). Also, both of these seminal studies sample providers and patients in the same locale to acknowledge the role of socio-economic factors play in patient/provider encounters. For example, Cohen et al (1994) attempted to homogenise their study participants in their study by sampling patients from middle class, professional backgrounds. This was done to bracket out socio-economic factors as a contributing factor to differences in health ‘explanatory models’. Cohen et al. found that low divergence between provider and patients’ explanatory models corresponded positively with successful maintenance of recommended HbA1c readings. This suggests that greater congruence between provider and patient understandings produces better clinical outcomes. However, Hunt and Arar counter that during the repeated clinical encounters that long term conditions engender, patients develop concepts of illness that reflect the terminology and expectations of health professionals. Instead, Hunt and Arar (ibid.) highlight that where good clinical control was attained by the patients in their sample, this conflicted with the patients’ day-to-day goals, strategies and evaluation. Therefore, by placing the experiences of a low-income ethnic group on an analytical par with health care professionals’ perceptions, the authors were able to interrogate how the everyday practical concerns are used by patients to assess the utility and applicability of health professional recommendations. However, there is little investigation offered in Hunt and Arar’s (or Cohen’s) study as to how socio-economic factors interplay with patients’ experiences of illness, or providers’ perceptions of these
patients. This omission gains increasing pertinence as health outcomes in T2D are correlate with specific socio-demographic groups in modern healthcare systems (Brown et al., 2004).

Yen et al. (2010) interviewed a variety of Australian healthcare professionals (n=88) using focus groups, and explored their responses to qualitative data taken from a preceding study exploring patients’ experiences of managing chronic illness (including T2D). The analysis of the patient data had shown that patients and their carers reported three main areas of difficulty in managing chronic illness. These were: 1) economic hardship; 2) managing co-morbid conditions; and 3) juggling clinical recommendations with the desire to lead a ‘normal life’. Similar to Hunt and Arar, Yen et al. (2010) found that healthcare professionals agreed that these areas were problematic for patients managing chronic illness. However, mirroring Hunt and Arar’s (1994) study, professionals saw patients’ problematic experiences as stemming from failures to comply with professionally-recommended advice. One example of this being where a patient discussed economic hardship in terms of the budgeting and transport costs associated with accessing healthcare. Professionals’ responses equated this barrier as the patient having poor priority-setting skills.

Building on the findings of Hunt and Arar’s study, Yen et al. (2010) found that professional understanding often converged with patient understanding, although in some instances there were some substantial semantic differences. Professionals in the study acknowledged that some areas of difficulty experienced by patients could be related to this service fragmentation, i.e. as a result of systemic failings. So, whereas systemic failure in the form of service fragmentation was reported by patients as contributing to economic hardship - through increases in costs of access; Providers saw systemic failing as poor interprofessional working, or poor service infrastructure that created access and cost issues for patients. This overlap, with semantic differences in the reporting of barriers to care is supported by the work of Peyrot and Rubin (2008) who found similar issues in relation to self-management education. However, Yen et al’s (2010) study also found that whether
or not the difficulties patients experiences were perceived by professionals as related to individual ‘compliance’ factors or systemic ‘service fragmentation’ factors, professionals tended to frame the prime solution as lying in increasing resources for their own activities, and those of their profession. This study added to the literature by finding that many professionals do see systemic factors in T2D management as having impact on service delivery (and hence, the provider level) which, in turn, is seen to impact on the patient (self-management) level and patients’ experiences of care, but, there is little discussion of the fit between provider and systemic factors with the day-to-day life experiences of patients. However, Yen et al’s (ibid.) study refines the notion of separate interpretive and explanatory domains through noting the commonality of systemic factors on patient and provider experiences of managing T2D. In short Yen et al’s study introduces the idea of factors emergent from the context of healthcare but external to patients’ and providers’ perceptions, which nonetheless still shape the content of their experiences, understanding and perceptions of managing T2D. The study also suggests some overlap between the interpretive domains of patients and providers occurs.

Pooley et al (2001) explored differences between patient (n=47) and provider (n=38) on their views about effective management of T2D using semi-structured interviews. This UK-based study found five key themes relating to:

1) Having sufficient time in consultations;

2) Continuity of care;

3) Ensuring good patient-provider consultation;

4) The importance of ensuring patient concerns are heard and incorporated into planning; and

5) The importance of acknowledging each individual’s needs.
Differing from aforementioned studies, patients’ and providers’ perspectives both converged and diverged (in both patient and professional groups) on why each one of the aforementioned areas were important. Both groups agreed that institutional structures and constraints (systemic factors) frustrated the type of services they wished to receive or deliver, and both groups agreed that lack of time damaged the quality of patient-provider consultations. The study found that professionals and patients agreed that patients have well-informed realistic views about their health and accepted that they ‘owned’ the primary responsibility for their own health. Pooley et al. (2001) thus suggest that given that many of the ingredients needed to ensure empowered self-management were present in the views of the patient/professional sample, systemic factors were inhibiting patient empowerment - as opposed to clashes in the separate interpretive domains of patients and providers. Of note, however, is the fact that no income details were taken from patients, and the study states that elderly people were under-represented in the study – both income and age have been described as potential barriers to empowered self-management (Watt and Ponto, 2008; Newton and Asimakopoulou, 2008; Asimakopoulou et al., 2012; Brown et al., 2004; Gomersall et al., 2011). This suggests omission of the role of socio-contextual factors in Pooley et al’s (2001) study.

Bounthavong and Law (2008) found that patients’ and providers’ views where highly congruent when defining and ranking how diabetes impacted on health related quality of life. Qualitative interviews with patients (n=38) and providers (n=12) were analysed to define areas where diabetes impacted on health. It was found that both groups defined five similar areas: emotional well-being, social functioning, medication-taking and diet, and economic resources. However, their views diverged with regard to preventing complications and lifestyle modification – as patients did not consider these as resources necessary to having a good healthy quality of life. The authors also argue that the overlaps are semantically distinct with providers focusing on clinical and
process outcomes in self-management, and patients on their physical and social functioning in
day-to-day life.

Colaguiri and Eigenmann (2009) used a series of surveys and qualitative interviews to interview
patients, professionals and policymakers in Australia with the aim of developing a consensus of
how the goals and outcomes of diabetes education programmes should be measured. They found
agreement in the following areas: optimal adjustment to living with diabetes; optimal health
(physical) outcomes; and optimal cost-effectiveness (for the individual and for society).
Consensus also surrounded the concept of ‘living with diabetes’ (the patient level) which was seen
as having four elements: knowledge and understanding, self-determination, self-management; and
psychological adjustment. The consensus reached suggested that optimal cost effectiveness as a
goal (relating to both systemic and socio-economic factors) should be measured at the service
level using indicators such as self-monitoring of glucose; as well as at the population level using
indicators such as self-care practices. Physical outcomes remained rooted in clinical
recommendations. One shortcoming of the study is that despite clinical work being held on par
with systemic and patient issues in this study, there is little interrogation of provider-related
issues.

Hence, although this work and others (Lowes et al., 2010) find consensus at this broad level on
clinical recommendations, the work of Tang et al. (2006) and Yen et al. (2010) suggests that
patient and provider perspectives are often at odds in terms of definitions, sources and solutions to
optimal health outcomes. Zoffman et al. (2008) reach similar conclusions to Pooley et al. (2001),
suggesting that patients and providers draw from both the ‘disease-orientated perspective’ and
‘life-orientated perspective’ in communicative encounters – but suggest that shared decision-
making is only possible where practitioners and patients mutually engage in reflecting on the
patient’s situation and working out person-specific solutions. The authors (2008:682) suggest that
this approach can “...close the gap between two apparently conflicting ideologies: patient-centred
practice and evidence-based practice [...] and through mutual situational reflection can close the gap by co-creating person-specific evidence as a supplement to general evidence.”

Studies have continued to explore this issue of patient and provider communication differences as a result of the incompatible interpretive domains (Johnson et al., 2006; McIntosh et al., 2010). Tang et al (2006) refined the concept of divergence and convergence by saying providers’ understanding of T2D are denotative, referring specifically to the clinical context; Whereas patients’ perceptions are connotative, formed from issues such as family, work and other relationships. They also found that the gap in congruent understanding with healthcare professionals was greater for ‘African-American’ people living with diabetes than their white counterparts. The study was unusual as it paired patients with their actual care providers (n=130 pairs) and found that greater differences in semantic understanding led to poorer health outcomes. They found that patients were generally willing to manage their diabetes and even positive about their prospects. Rather, Tang et al (2006) suggest that providers tend to only see a snap shot of the patients’ concerns in the clinical encounter. As a result of this, they tend to hear about the patients’ psychosocial concerns during consultations which they do not see as matching their professional, clinical concerns and they are therefore less positive about the patients’ ability to manage their diabetes.

Role expectations of patients and healthcare professionals

Some studies move away from the theme of interpretive domains, to look at the roles healthcare professionals and patients adopt. The perspectives and behaviours of patients and providers are framed within situational contexts and there is greater room in the analysis to explore relational aspects of the patient and provider perspectives – as well as social and systemic factors. Skinner et al. (2007), recorded T2D-related consultations between patients and healthcare professionals, then afterwards asked both to recall the main decisions that had been made during the consultation.
Skinner et al. (2007) found that patients and professionals disagreed about the self-care goals that had been decided upon in consultations in around 50% of instances. The work also showed that when reported goals of the consultation were compared with the original recordings, patients remembered on average 0.6 of the 2.2 aims agreed upon in consultations, and both healthcare professionals and patients regularly recalled decisions that had never actually been discussed in the consultation. This suggests that outside these conflicting interpretive domains (or as a result of it) are issues of recall, and the notion that professionals and patients may just routinely ‘talk past each other’, taking what they will from consultations. Semantic differences therefore, may just be symptomatic of deeper micro-interactional problems, which again, has significant implications for T2D management approaches based on shared decision-making.

Kaae et al (2011) look at styles of communication between providers and patients but rather than looking at semantic differences, they focussed on the roles health professionals adopted when communicating with patients and other professionals. The researchers looked at the medication review process using documentary analysis, and considered how pharmacists communicated with GPs and with patients. They found major differences in both the style and content of the written correspondence of pharmacists when communicating with GPs and patients. Pharmacists were more likely to cite evidence and refer to clinical papers when writing to GPs about medications, whereas they were more likely to give instructional, paternalistic advice to patients. The most telling finding was that patients were frequently steered toward discussing any identified problems, e.g. drug side effects, with their GPs, whereas pharmacists hardly ever recommended that GPs discuss any identified problems with their patients. This study is interesting, as it shows how professionals ascribe different roles to patients and other healthcare professionals in their day to day work often tacitly excluding the patient from important decision-making processes.

Fagerli et al (2005; 2007) contrasted healthcare professionals’ and patients’ views around dietary advice for T2D in Norway. The research found that professionals reported a role dilemma when
treating patients from ethnic minority groups. This role dilemma centred around healthcare professionals drive to deliver care in a patient centred fashion - but perceiving that these patients frequently wanted them to adopt a more authoritarian, paternalistic style. When contrasted with the patients’ experiences, this premise was found to be false. Patients reported that they expected to be treated with empathy and care and to be guided by professional knowledge. Fagerli et al. (2007) found that individuals from minority ethnic groups had diverse levels of integration into society, and this diversity was an important consideration in the capacity to engage with shared decision making models. Interestingly, Fagerli et al. suggested that religious affiliation and cultural differences were barriers in communication mainly due to professionals’ stereotypical assumptions that these were problematic barriers, rather than these phenomena creating communicative obstacles in their own right. Rather, the study concluded that shortcomings exist in attempts to level-off the status differentials in clinical encounters, and that health professionals should rather,

“...admit their professional expert role and combine this with a caring attitude...” (Fagerli et al., 2007 109).

This suggests that although convergence and divergence between the interpretive domains of patients and healthcare professionals occurs, it is intricately connected to different role expectations, as well as to systemic and social issues that precede the patient/professional relationship. Fagerli et al. suggest that socio-economic factors (relating primarily to class) are a key concern, as material resources are a major influence on the circumstances patients face in everyday life. The authors argue that patient-centred approaches should also focus on provider roles to ensure that asymmetries in power and knowledge are made explicit in clinical encounters (and open to negotiation), that providers maintain their responsibility to care for patients, and that patients should be able choose the level of involvement or degree of empowerment they wish to practice.
Similar findings were made in Goyder et al.’s (2009) UK study contrasting the views of patients being screened for diabetes with the views of professionals providing screening. Similar to Fagerli et al (2005; 2007), the study found that patients expected professionals to make the decision to screen for T2D on their behalf, and in their best interests. Healthcare professionals in the study, however, believed the patients had made an informed choice as they had received either a written or verbal invitation to screening which outlined the potential risks. The work of Goyder et al (2009) suggests a relational aspect to the clinical encounter. Patients and professionals were seen to have pre-formed role expectations which shape their understanding, and further to this read cues of each other's behaviours, responses and roles which inform patients’ perception of the clinical encounter, and professional perceptions of patient behaviour and capacity. Hence, it appears that there is a cross-pollination and convergence of role expectations and interpretive domains which impacts on both provider and patient perceptions, understandings and experiences.

In overview, we can see, many commentators contrast patients’ and professionals’ perceptions of managing T2D looking for congruence and divergence in the perceptions, understanding and experiences at the patient and provider levels. Studies have also begun to highlight the role systemic factors (Pooley et al., 2001; Yen et al, 2010), and socio-contextual factors (Mcintosh and Singh, 2010) play in shaping patient and provider perceptions, understanding and experiences of T2D, and its management. Contrast studies have continued themes established in seminal works such as Hunt and Arar (2001) and Cohen (1994) relating to separate interpretive domains, as well as congruence and incongruence between patients’ and providers’ viewpoints. Indeed, Ritholz et al.’s (2011) review of qualitative approaches to diabetes concluded that patients and healthcare providers perceive similar problems in communication in clinical encounters, and that both parties were dissatisfied with this communication deficit. Pooley (2001) married together the concepts of systemic factors and interpretive models in finding both congruence and divergence within and between patients and professionals views – as a general agreement between both groups about the
role of systemic issues in creating barriers to T2D self-management was found. However, some commentators suggest that much of the congruence found in patient-provider perception is the product overlooking semantic differences, and precluding differences between the strategic, evaluative and assessment criteria patients and professionals use in T2D management (Tang et al., 2006; Hunt and Arar, 2001). Focusing on congruence and divergence of patients’ and healthcare professionals’ perspectives may inadvertently create an analytic ‘sleight of hand’ – where relational aspects of the patient-provider relationship and T2D-related factors are bracketed out of the professional/patient interface – and where connections to socio-contextual factors are underplayed. Studies have emphasised the area of cross-pollination between healthcare professionals and patients and the role that status differentials, role expectations and communication can play in both groups misinterpreting or misunderstanding the perceptions, understanding and experiences of the other (Fagerli et al, 2005, 2007; Goyder et al, 2009; Skinner et al, 2007).

In conclusion, we can see patient-specific literature and healthcare professional-specific literature which explore how both groups manage T2D on a day-to-day basis, as well as these groups’ criteria for judging how T2D should be managed successfully. So too, the barriers and enablers that facilitate and constrain T2D management are explored in the patient-specific literature and healthcare professional-specific literature. Equally, studies comparing and contrasting patients and healthcare professionals highlight how perceptions, understanding and experiences can converge and diverge shaping both criteria used to gauge the management of T2D, as well as the barriers and enablers both experience.
Chapter Two – Methodology

Epistemology, Methodology and Methods

Chapter headings:

Introduction

2.1. Theoretical framework

2.2. Sampling

2.3. Data collection techniques

2.4. Data analysis

2.5. Reflexivity, validity and reliability strategies

2.6. Ethical issues
Introduction

This study used a qualitative cross-sectional study design employing heterogeneous sampling technique and mixed methods of data-collection. The data was analyzed thematically using framework analysis. To give an overview of the methodology and methods informing these processes, the chapter begins by giving a brief summary of the critical-realist theoretical framework of the research - which informed the study’s methodology. The chapter then goes on to discuss the sampling aims and recruitment strategies employed in the study as well as the outcome of the sampling method. The data collection and analysis techniques adopted and the justificatory assumptions underpinning the adoption of these techniques are then outlined. The chapter also briefly outlines the strategies put in place through research design to promote validity and reliability of data. The final section looks at how ethical issues were addressed.

To recap, the main aim of the present study was to compare and contrast patients’ and healthcare professionals’ perceptions, understanding and experiences of managing Type 2 Diabetes (T2D) within a healthcare environment where the empowerment approach was the prevailing paradigm. The research questions in support of this aim sought to answer:

1) What are patients’ and healthcare professionals’ perceptions, understanding and experiences of successful and unsuccessful (un/successful) T2D management?

2) What barriers and enablers do patients and healthcare professionals perceive, understand and experience in relation to managing T2D on a day-to-day basis? and

3) What similarities and differences emerge in patients’ and professionals’ perceptions, understanding and experiences of managing T2D on a day-to-day basis?
2.1. Theoretical Framework

The present study adopted a critical realist stance to inform its theoretical framework. Sayer (2000: 2) states “...the defining feature of realism is the belief that there is a world existing independently of our knowledge of it”. As such, the world is seen as having depths beyond what we know about it. For seminal critical-realist Bhaskar (1979), reality is stratified into three layers or domains - the ‘empirical’, the ‘actual’ and the ‘real’.

The empirical domain describes the realm of events and experiences. We can illustrate this using the example of a scientific experiment where an ‘event’ occurs, e.g. two substances are combined to create a new substance. This ‘event’ - of two substances combining - is experienced by the scientists present, and recorded using instruments of measurements that allow the scientists to interpret the event (these measurements again rely on the scientists’ senses). As such, the event creates phenomena that can be experienced - so put simply, the empirical domain of reality comprises of both events and experiences.

However, Bhaskar (1979) notes that not all events that occur are necessarily experienced, and that events can occur regardless of whether we experience the event or not. Bhaskar (ibid.) argues that as events occur independently of experiences, they occur in the separate domain of reality he calls the ‘actual’ (a domain comprised solely of events) – e.g. the event of two substances combining to form another substance. Hence, although events create effects which can be observed and experienced in the empirical realm, in the actual realm only the event occurs,. Therefore, aspects of this event may or may not be experienced in the empirical realm.

Following on from this, Bhaskar (1978:12) argues that “…there is an ontological distinction between scientific laws and patterns of events”. As such, scientific laws depend upon the existence of ‘natural mechanisms’, therefore “…it is only if we make the assumption of the real
independence of such mechanisms from the events they generate that we are justified in assuming that they endure and go on acting in their normal way outside the conditions that enable us to empirically identify them” (p. 13). To continue the example, as the two substances combine and consistently create the same ‘new’ substance when the experiment is repeated, we must assume a stable, overarching mechanism governs the process. Hence, Bhaskar (1979) argues for a further distinct realm of the ‘real’, comprised solely of generative mechanisms (also known as ‘causal’ mechanisms), which are separate from the domain of events. Bhaskar (1979) refers to this domain of the ‘real’ as having enduring emergent properties (also called generative mechanisms/structures or causal power) - which give rise to events that occur in the actual realm. These events create traces in the empirical realm which we interpret (albeit with fallibility). This interrelated nest of domains is referred to by critical realists as the three domains of the real (see figure below):

![Diagram](image.png)

**Figure 1: The three domains of the real in critical realism**

For Bhaskar most natural and social scientific approaches involve only a superficial exploration of reality. One key criticism Bhaskar levels at natural and social sciences is that of the epistemological fallacy. This occurs when questions of ontology – or ‘what is’ – are reduced to
that which is known about them. For example, the scientist writing up the findings of the experiment may observe dependent and independent variables which behave in certain ways in certain circumstances, and this verification process is seen as a sufficient basis for the description to be considered a reality. However, the variables described may correspond with the scientist’s experience of what was observed, but they cannot describe what happened in the domain of the actual (all the facets of the event that happened) or the domain of the real (the power by which the mechanism/s consistently generate the event). Thus, Bhaskar calls for research to explore events and experiences as traces of generative mechanisms (in domain of the ‘real’). That is, the focus is not usually on the specific event observed (Type 2 Diabetes, in this study), but on what that event tells us about enduring underlying causal relationships (generative mechanisms) that lie beyond and inform common experience (i.e. the processes shaping the management of T2D in the ‘empirical domain’).

Within the social sciences critical realism has played a major role in the debate between structural explanations of human behaviour – how living in a society influences individual behaviour; and agentic explanations of human behaviour – how individuals shape their own circumstances (Archer, 2007). Whereas some social scientific approaches - such as phenomenology and rational-choice theory, see agentic/individual behaviour as a key contributor to how people make their way through the world; other approaches – such as Marxism, poststructuralism and social constructionism - emphasize the role that living in a society plays in shaping a person’s behaviour. For critical realists these approaches represent an epistemological fallacy as both approaches conflate the causal mechanisms of behaviour with either the actions of individuals, or with the effects of socialization. As such, theories based on these types of epistemological fallacy tend to address only one side of any issue by reducing the causes of behaviour to either the individual or social influences. Therefore, Archer (2000) argues that an epistemological fallacy is evident in much social-theorizing through the conflation of structure with agency. As Archer (2000:5) states:
“Basically conflationists reject the stratified nature of social reality by denying that independent properties and powers pertain to both the ‘parts’ of society and to the ‘people’ within it... In Upwards Conflation the powers of the ‘people’ are held to orchestrate those of the ‘parts’; in Downward Conflation the ‘parts’ organise the people.”

Archer (2000) also describes ‘central conflationists’ who see agency (individual factors) and structure (social factors) as so closely interrelated that reciprocal or independent influences between the agency and structure cannot be teased out (Archer, 2000).

Rather critical realism sees structure as having characteristics (causal powers) that naturally emerge, and people engage with:

“…[P]eople do not create society: for it always pre-exists them and is a necessary condition for their activity. Rather, society must be regarded as an ensemble of structures, practices and conventions which individuals reproduce or transform but which would not exist unless they did so. Society does not exist independently of human activity (the error of reification) but it is not the product of it (the error of voluntarism).”

(Bhaskar, 1979: 45-6)

One example of an emerging property of structure is given by Archer (2007) who notes that there are finite material resources (e.g. money, employment, or goods) and/or social resources (social support or information) in any society, and therefore, people will have different, and often unequal, access to these resources. As such, structures create an array of social contexts with different resources, and people will organize themselves in different ways to access and distribute a given resource. Equally, individual behavior is seen to be an emergent property. Archer (2007) describes a range of natural sensory, emotional, bodily and socially-referent characteristics which emerge from our sense of self as personal concerns, e.g. revulsion, upset from loss, feeling hungry and seeking comfort from others (respectively).

Therefore, critical realist approaches see people’s perceptions, understanding and experiences as part of a ‘social identity’ which develops as people navigate their way through their personal
concerns and their social context. This social identity is ‘reflexive’, that is to say – it is a process of people reflecting and managing their personal concerns in relation to their social context/s, and managing and responding to the social context/s in relation to their personal concerns. For example, a person with T2D may be concerned by their high blood sugar readings and interpret this as a personal failure as they wished to gain greater control over their dietary practices – all personal concerns. However, the individual has a large family to feed, a tight budget (as the person is currently unemployed) and there is a shortage of work due to an economic recession (all relating to social context). For Archer (2007), when people are deciding whether or not to act on an issue, they ‘mull over’ and/or develop strategies to address their personal concerns in light of their social contexts, and assess their social contexts in light of their personal concerns before developing a plan of action. Therefore, the person living with T2D (above), may anticipate and worry about the impact that falling ill will have on their ability to looking after their children, but weigh this against the cost of buying healthier, more expensive food on the family budget. Therefore, it is possible using the critical theorist framework, to explore the personal issues people consider in managing their T2D, such as personal understandings of T2D and the stage the condition has reached. As well as, issues in their social context, this social context can relate to the healthcare system and to the underlying social structures (social class, gender and so forth) which shape the circumstances, and provide the resources through which people experience, understand and live with T2D.

2.2. Sampling Strategy

Qualitative studies, such as the present one, seek to answer ‘why’, ‘how’ and ‘what’ questions from the perspective of the research participant (Lacey and Luff, 2009; Bowling, 2002). Thus, intrinsic to the qualitative approach are ramifications for how samples are selected (Holloway and
Wheeler, 2010). To illustrate with an example, a researcher may wish to explore: Why people living with T2D co-morbidities find it difficult to follow diet advice?

In answering this question, a quantitative research approach may use techniques such as structured questionnaires, attitude scaling, alongside measurements of standard outcomes, such as blood glucose and nutritional intake to test an initial hypothesis - then identify associations and correlations between variables. This quantitative approach may, for example, aim to find out which types of T2D-related co-morbidities are associated with being less likely to follow dietary advice. Important as this finding is, this approach gives us little understanding of why those who have these T2D-comorbidities are consistently less likely to follow dietary advice.

A qualitative approach, on the other hand, would seek to gain insight from the perspective of people living with T2D co-morbidities to answer the same question. This could be through in-depth interviewing, ethnographic observation or focus groups with people living with T2D co-morbidities. As such, the aims of the research would shift to exploring why, and how, living with a T2D-related co-morbidity impacts on a person’s ability to follow dietary advice. For example, the study may find that the participants interviewed reported experiencing a reduction in mobility with the onset of T2D-related co-morbidities (due to pain and their families insisting on helping them) leaving the participants with less control over what they eat.

From this example, we can see that quantitative approaches would require a large sample of people living with T2D co-morbidities to increase statistical power and demonstrate generalizability across the selected population, as well as to be confident about the associations and correlations between variables researched (Lacey and Luff, 2009; Bowling, 2002). On the other hand, qualitative approaches would seek to secure in-depth data showing causal relationships rooted in the perspectives, understanding and experiences of those living with T2D-comorbidities (Ritchie et al, 2006a). Hence, qualitative studies do not seek to create findings
generalizable to the whole of the population – but rather seek to capture the lived, in-depth insight and understanding of those with experience of a given issue. Therefore, qualitative studies usually have fewer participants than quantitative studies because the depth of the data collected from each participant does not allow for, or require, large numbers of participants across the given population. Also, as depth of the data is sought, small samples ensure that data remains manageable, and that the data does not become ‘saturated’ – i.e. the data answering the research question becomes repetitive to the point where further recruitment of participants is unnecessary (Silverman, 2006).

Therefore, qualitative studies usually incorporate some form of purposive sampling, where participants or settings are selected based on criteria related to the area being studied - the reason for this is two-fold. First, random sampling of a population is likely to produce a representative sample only if the research characteristics are normally distributed within the population. As qualitative studies usually address issues unique to specific people (e.g. a person managing T2D), non-purposive samples are not suitable (Holloway and Wheeler, 2010). Secondly, qualitative researchers explicitly recognize that some people are better able to provide insight and understanding into a research area (Bowling, 2002; Marshall, 1996). For example, asking a sample of ten car mechanics about the best way to mend a broken carburetor is more likely to yield pertinent information than asking 100 passers-by on a high street.

2.2.1. Sampling

The key purpose of this study was to explore healthcare professionals’ and patients’ perceptions, understanding experiences of managing T2D in a social context that promoted an empowerment approach to T2D management. As such, the study adopted a qualitative approach, purposively sampling people living with T2D to reflect diversity in social background and severity of T2D in patients, and healthcare professionals providing these patients with care and treatment. Implicit
within the research aim were three inclusion criteria which informed the sampling aim. The research aim required specific characteristics from potential participants in the study. The first requirement was that (1) the patients recruited to the study were living with T2D. Secondly, it is also a requirement of study’s aim that (2) the patients (and healthcare professionals) sampled be actively engaged in T2D (self-) management. The third criterion was that (3) the healthcare professionals recruited to the study be actively involved in the care and treatment of the patients who were sampled – to ensure that both sets of participants were drawing their experiences from the same health context. Finally, it was important that (4) the healthcare professionals and the patients be engaged in a healthcare context that purported to ‘empower’ patients.

Added to this, and in light of the literature presented in the previous chapter, studies of patients’ experiences of managing T2D are often limited due to the tendency to use homogenous samples. As discussed in the previous chapter, homogenous samples tend to preclude investigation of the role that socio-demographic factors (e.g. income) and T2D-related factors (e.g. progression of the condition) play in patients’ perceptions, understanding and experiences of T2D management. In order to avoid this limitation, the present study sought (5) a single geographic health locale with a diverse socio-demographic population with the potential to capture heterogeneous sample. Heterogeneous samples (Robson, 2002; Patton, 2002; Holloway and Wheeler, 2010) sample a group and/or setting purposively to ensure differences between potential participants (Ritchie et al, 2006a; Faglerli et al., 2007). Here, a group-based approach was taken to capture naturally occurring diversity of people living with T2D in the borough and a variety of different healthcare professionals. Variation of patient participants was sought, in particular, in relation to socio-economic background, as well as stage of illness. The study sought to recruit 30–40 patient participants through a mixed method of data collection. This enhanced the potential for meeting a saturation point with the data collection, as well as allowing for triangulation between data-collection methods (discussed further below). Silverman (2006) describes ‘saturation point’ as a
point arrived at when the information that is being shared with the researcher becomes repetitive to the degree that the researcher can be reasonably confident that the inclusion of additional participants within the current sample is unlikely to generate any new ideas (this usually occurs around 20\textsuperscript{th} to 25\textsuperscript{th} interview). Thirty to forty patient participants is commensurate with ‘contrast’ previous studies (e.g. Pooley et al., 2001; Fagerli, 2005, 2007; McIntosh et al., 2010). For healthcare professional participants, variation was sought in relation to their role in T2D management. Due to the potentially small pool of healthcare professional participants to draw from (N=28 professionals were associated with the Participation Group), the study sought to recruit 10-15 healthcare professionals in various professional roles, and to collect data from these participants using in-depth, semi-structured interviews. These numbers are commensurate with participant numbers in previous ‘contrast’ studies (e.g. Bountavong and Law, 2008; Johnson et al., 2006; McIntosh et al., 2010; Fagerli et al., 2005, 2007) and studies looking solely at professionals’ perceptions (e.g. Asimakopoulou et al, 2012 and Scambler et al., 2012).

2.2.2. Sample Recruitment

Having established the criteria by which to sample participants, the researcher contacted the Patient Advice and Liaison Service (PALS) at the local NHS Trust for a London borough with a diverse local population, to enquire about ways of contacting groups of professionals and patients who managed T2D. Two sources of a potential sample did not meet the sampling aims:

1) One option was recruitment through diabetes-related consultant clinics or general practitioner (GP) surgeries – this convenience sample approach was rejected as there were no guarantee that those agreeing to take part were actively engaged in self-management (i.e. the potential patient participants may not be engaged in making any conscious attempt to self-manage their illness). Equally, the associated healthcare professionals (consultants
or GPs) may not identify themselves as working in a healthcare context purporting to be practicing in an empowering fashion;

2) The second option discussed with PALS was accessing participants through Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) courses was also unsuitable. This method of recruitment was not considered as this would have produced a sample whose perceptions, understanding and experiences had been uniformly influenced by attendance at the same educational course. Although, there was the possibility of sampling the waiting list for the course, DESMOND courses are predominantly populated with the newly diagnosed who are referred by their GPs, and hence there is a potential for an overly homogenous sample (and again there is little certainty that the potential participants are actively self-managing their T2D whilst on the waiting list).

The PALS also suggested a local Diabetes Participation Group. As will be outlined below, this offered access to a sample of healthcare professionals directly associated with people actively living with, and self-managing, T2D, all of whom were members of a group purporting to empower patients which was located in an area characterised by socio-demographic diversity. Following discussions with the group (both healthcare professional and patient members) the Group Leader agreed to facilitate the researcher’s access to the group to conduct the research.

**The Diabetes Participation Group**

The Diabetes Participation Group selected was sponsored by the Local Health Trust and co-ordinated by the Trust’s Participation Officer. The Diabetes Participation Group is an initiative of a local Diabetes Partnership Network (comprised of healthcare professionals in the local Trust). All healthcare professionals in Southwark were encouraged to refer people living with T2D to the Diabetes Participation Group, and attendance was voluntary. The Participation Group held four
monthly meetings in different wards of the borough (usually timed so all wards can attend a meeting if they choose), and all people living with diabetes are invited to attend the meetings (by healthcare professionals across the borough). At the time of the study the group had 166 members, all living with either Type 2 Diabetes. According to the Group Leader, there were also around 28 professionals who had varying degrees of involvement in the Diabetes Participation Group. The Group was selected for recruitment as it met the criteria of the sampling aim. First, the group was an open–membership scheme for the T2D population in the local area, and founded on the purported principle of empowering patients to self-manage. Secondly, the Group had associated healthcare professional members who supported the Participation Group, these healthcare professionals also worked locally providing care and treatment to the patient members. The group also offered as a heterogeneous cross-section of the local T2D population who were living with, and actively self-managing T2D (i.e. by virtue of seeking information and support through the Participation Group). Equally, the borough selected for the fieldwork hosts a diverse population – incorporating wards ranked within the 10 per cent of the most deprived areas in the country, with adjacent wards being amongst the wealthiest in the country.

*Healthcare professional sample*

As noted, sampling through the Participation Group offered access to a group of healthcare professionals associated with the patient group, and membership of the Participation Group by healthcare professionals demonstrated support of the purported aim of ‘empowering people living with T2D’. In total 10 professionals were recruited from a variety of backgrounds. Healthcare professional participants were known to patient participants from the primary care appointments, hospital consultations and the group itself. All contrast studies discussed in the previous chapter formulate their samples in a manner so as to ensure that the patient and healthcare professional population are associated. The work of Pooley et al. (2001) and Fagerli et al. (2005, 2007) used a single health locale to ensure that patient respondents would have had contact with the healthcare
professionals - with Fagerli et al. (2005; 2007) sampling a Norwegian Participation Group for a contrast study (suggesting this is an effective sampling method for contrast studies). Due to the multi-dimensional nature of T2D patients receive services across primary and secondary healthcare - this was reflected within the healthcare professional sample ‘population’ as a whole - with healthcare professionals occupying roles within and across each of these sectors.

2.3. Data collection

Data collection, occurred between September 2006 and March 2007. All interviews and focus groups were conducted by the researcher (Paul Newton). In order to increase participation by patient participants, potential participants were given the choice of taking part through a range of data collection methods, and to participate through more than one format. Potential patient participants could choose between focus groups (and/or), qualitative questionnaires (and/or), one-to-one interviews. In order to collect rich, detailed information, healthcare professionals could only take part in semi-structured one-to-one interviews. In total thirty-seven (n=37) group members of the participation group were recruited as participants (in total there were a potential n=166 group members to capture) and were interviewed using focus groups, semi-structured interviews and qualitative questionnaires. In terms of recruitment to data-collection method within the patient sample, twenty-five (n=25) one-to-one interviews were conducted, 6 questionnaires were returned and 11 people attended 3 focus groups (n=3,3,5 attendees). Only five (n=5) respondents used more than one method, one questionnaire respondent called the researcher to request a one-to-one interview, and 4 focus group respondents went on to do one-to-one interviews. Over the same period, a total of ten (n=10) professional interviews were conducted. A figure of the research process and number participating is given below:
Figure 2: The Research Process
Ritchie et al. (2006a) and Bowling (2002) suggest that when working through an organisation to obtain a sample, it is important to attempt to gain the views of those who are not in contact with the service. However, both of the aforementioned authors also note that this is unnecessary when the focus of the study is around interaction between people using the service and service providers – as is the case here (Ritchie et al., 2006a and Bowling, 2002). However, both Ritchie et al., (2006a) and Bowling, (2002) also note that it is important to work closely with the organisation to maximise participation in the study – and thus increase the potential for a heterogeneous sample. As patient membership of, and professional association with, the group was voluntary, attendance for both was highly variable. Thus, the researcher worked closely with the Group Leader and a group member to ensure participation was maximised for collecting data. Key concerns for the group representatives were:

- Ensuring that group members had different ways to take part in the research (for example, many patient members had mobility issues (and prefer a questionnaire), and it was suggested that members may prefer having taking part in one-to one or group data collection formats);

- In discussion with the group members it arose that the definition of ‘people living with T2D’ should include spouses and family members. Hence, spouses, family members and others in significant caring positions were invited to take part in the research alongside those living with T2D (co-interviews).

Consulting with the group prior to designing the study improved the design of the data collection instruments in a variety of ways that complemented the sampling strategy. The consultation with the group leader highlighted the need for mixed methods of data collection to maximise participation (and, thus for the potential of increased heterogeneity within the sample). Secondly, multiple data collection instruments meant that it was possible to triangulate between methods to check that the findings developed were not (overly) biased by the researcher or the data collection format to increase the reliability of the data (Mays and
Pope, 2000; Bowling, 2002 and Cresswell, 2007). Also, Barbour (2001) notes that although varying data-collection methods produces vastly different data formats which require ‘crystallisation’ to a single format, the range of data collected frequently refines the comprehensiveness of the results as well as internal validity – i.e. comparison of content between methods strengthens the causal inferences identified (see also Mays and Pope, 2000). Studies in the contrast literature have also previously triangulated between qualitative data-collection methods (e.g. Colaguiri and Eigenmann, 2009; Pooley, 2001).

2.3.1. Introducing the research and recruitment of group members

Introductory sessions with the group of potential patient participants were held with all 4 different branches of the Diabetes Participation Group. At the meeting prior to the introductory sessions, the group had been informed that a researcher would be attending the next meeting to explain the study. Using the Participation Group newsletter, members were given a brief description of the research (to give them a choice of whether or not to attend the brief introductory session presentation). The description explained that members could participate as much or as little as they wished and they could return a questionnaire and/or, opt for a one to one interview (healthcare professionals) and/or attend a focus group (patients). The group leader also wrote to each group member and health professional associated with the group, stating a researcher wished to contact them via mail with regards to taking part in a research project (See cover letter in Appendix 2 a). The potential participants were asked to respond to the letter if they did not wish to be contacted in this manner (in accordance with the Data Protection Act, 1998). They were also given an explanation of the study. No potential participants declined to be contacted in this manner by the researcher. One month later all group members and healthcare professionals were sent a cover letter, a participant information sheet and a consent form (see Appendix 2 a, b, c for patient versions and Appendix 2h, 2i & 2c for healthcare professional versions) for information purposes.
Patient respondents were also sent a qualitative questionnaire and pre-paid envelope to allow them to take part in this manner (see Appendix 2 f). The information sheet contained ways to contact the researcher with any queries. Arrangements were also made for the group to discuss participating in the research with the group leader in the three weeks before recruitment took place. The mail shot process occurred concurrently to the researcher attending the groups to introduce the research.

The researcher then attended the 4 group meetings (attended by n=23; 18; 21; 19 group members) with the aim of recruiting directly to the study. From the thirty-two (n=32) people who expressed an interest and gave their details to the researcher to make arrangements, thirteen (n=13) people agreed to do interviews only, eleven (n=11) signed up for focus groups, (4 of whom then went on to do interviews). At this stage, respondents who opted for an interview or focus group gave the researcher their details and were called in the following weeks to make arrangements for a time and date. A further eight group members contacted the researcher for a one-to interview all of whom had attended an introductory session (one having also filled out a questionnaire), i.e. no focus group respondents were recruited directly via the mail-shot. In fact, only the single respondent who filled out a questionnaire then requested an interview was recruited and the remaining 5 patients who filled out the questionnaire were recruited in this fashion. Over the same period, potential healthcare professional respondents (n=28) associated with the group were contacted and invited to take part in a one-to-one semi-structured interview. In total ten agreed to be interviewed.

### 2.3.2. Focus Groups

Focus groups were conducted at the venues regularly used by the group, to ensure easy access to an environment familiar to the participants. Three were conducted a week apart from each other. In total n=11 people attended n=3 focus groups (n=3,3,5 attendees). Focus groups lasted between 60-120 minutes. Interestingly, many of the respondents in each group had not
met before, as they attended differently located groups (within the overarching group), or changed their ‘location group’ frequently, and/or were irregular attendees.

The focus groups were intended to serve three main functions within the research. First, the focus groups provided data per se, i.e. actual qualitative content. The topic guide was designed to elicit participants' accounts of how their lives have changed since diagnosis, their experiences of managing T2D, their motivations for, and experiences of attending the group as well as whether and how this informed T2D management (See Appendix 2 d). Secondly, the dynamics of the focus group format meant that participants could absorb and respond to what each other had said, this synergistic process highlights central concerns in the topics discussed (Finch and Lewis, 2006). Thus, the processes of the focus group method were useful in establishing the everyday norms of a topic, e.g. common experiences, understanding and perceptions of managing T2D. Thirdly, these findings were invaluable in developing initial categories in the thematic framework during the analysis stage (Bowling, 2002).

Finch and Lewis (2006) suggest that focus groups tend to be more spontaneous and minimise interviewer influence. Focus groups are generally used to establish group beliefs and group dynamics (Munday, 2006; Clark, 2003). Both Alazri et al. (2006) and Elstad et al (2008) have used focus groups to explore patients’ experiences of barriers and enablers to successful self-management. However, Munday (2006) explored the content and processes of focus groups in members of the Women’s Institute, and contrasted these with the outcomes of semi-structured interviews. Munday’s findings showed that focus groups - within pre-existing groups in particular - tend to reinforce the collective identity, and/or the stated and unstated values of the group, rather than allowing for personal opinions to be revealed. The same participants (in Munday’s 2006 study) were seen to be more candid and opinionated in one-to-one interviews. Munday (2006) argues that the outcomes of focus group discussion tend to produce negotiated outcomes, hence, people will tend to criticise them privately and apply them selectively in their day-to-day life, or draw from the outcomes of negotiation aspects.
which reflect their own input. To counter this potential shortcoming and generate more variety in the data, patient respondents were also invited to contribute through one-to-one semi-structured interviews.

### 2.3.3. Semi-structured interviews

Semi-structured interviews were conducted with patient and healthcare professional participants, over a period of three months (following the focus groups). As with the topic guides of the focus groups, the interview schedules (questions) for healthcare professional and patient interviews were developed to address all aspects of the research questions (See Appendix 2e for more detail see also Appendix 2k for a guide as to how questions from each data-collection method relate to research objectives). Twenty-five (n=25) interviews were conducted with people living with Type 2 diabetes, as it was agreed by the researcher and the research supervisors that saturation point had been reached (in conjunction with questionnaires received and focus group data). In addition, ten (n=10) interviews were conducted with healthcare professionals associated with the group.

#### Semi-structured interviews with patient participants

Patient participants who took part in the semi-structured interviews (n=25) chose a time and place convenient to them, in an appropriately private venue - which the researcher organized at Kings College London, or at a place according to the participants’ preferences. In keeping with the notion of incorporating people ‘living with the management of T2D’, people close to patients who helped manage the condition were invited attend the interview (by the person living with T2D) and contribute to the interview process. In total, six (n=6) female spouses took part in co-interviews with the patient sample. Patient participant interviews lasted between 30-90 minutes.
A series of questions were developed, based on what was known from the literature to map content in key areas relating to how participants’ managed T2D on a day-to-day basis, their understanding and perception of successful and unsuccessful T2D management and any barriers and enablers they experienced in managing T2D (Legard et al., 2006). Content mapping questions were used to open up the research territory so that concerns, dimensions and issues important to the respondents could be established. The researcher followed this up with ‘content mining’ questions (ibid.). This entailed sub-questions and spontaneous prompts to allow the respondent to furnish their responses with details and useful personal examples of their concerns, as well as express the personal meanings and ideas that informed their views.

For example, the following question with sub-prompts was a question that yielded a wealth of information in patient respondents:

**How do you personally manage your diabetes?** (A content mapping question, followed by guided content mining questions)

- **How do you know when you are managing well or badly?**
- **Is it working for you?**
- **Do you look for help and advice about managing the illness?**

Semi-structured interviews are used in exploratory studies (such as this) to ask questions that are open ended, the idea being that semi-structured interviews create an opportunity for the participant to speak freely and for the interviewer to ask questions on the emerging content (Legard et al., 2006). Hence, by being inductive and personal to the individual, semi-structured interviews have an affinity with this study’s aim of capturing perceptions, understanding and experience. The use of open questions allowed for the researcher to respond to what interviewees say, and this encourages free talk within the clearly defined structure of topic guide or list of questions (Arthur and Nazroo, 2006; Bowling, 2002).
Hence, another motive for employing semi-structured interviews was to ensure ‘rich and thickly descriptive’ data was collected (Cresswell, 2007). Hence, due to their capacity for producing rich, detailed data semi-structured interviews were employed to capture the experiences, understanding and perceptions of healthcare professionals too.

**Semi-structured interviews with healthcare professional participants**

Having been introduced to the research through the Participation Group newsletter, and received an introductory letter requesting consent to be contacted about the research (see Appendix 2 h), healthcare professionals associated with the group (n=28) were called by telephone and asked if they would like to take part in a semi-structured interview. All 28 professionals were contacted over a 3 month period. In total 10 interviews took place. Interviews with healthcare professional participants lasted between 60-120 minutes, and the length of the interview was often agreed beforehand as healthcare professionals had to schedule time in their work days to take part. This professional sample of respondents was prolific in terms of data, with participants speaking for two hours or more in most cases (See Appendices 2 i, c & j for Interview Guide, Consent Form, Information Sheet respectively). It was important to protect the anonymity of the healthcare professional sample. Due to the small size of the potential sample, it would be easy to identify healthcare professionals associated with the group (particularly by other health professionals in the Trusts. Thus, transcripts were assigned a participant number, and the healthcare professional quotes used in the results section are not associated with the role of the healthcare professional. Equally, the names of the London borough, the Healthcare Trust and the Participation Group have been anonymised to further prevent identification of participants.

2.3.4. **Qualitative questionnaires**

Qualitative questionnaires matching the questions in the one-to-one interview schedules were given to all potential members of the group through the mail-shot. Only six (n=6) of the
potential 166 group members returned a completed questionnaire. Evidently this is a less effective recruitment method, perhaps, as Bowling (2002) suggests, due to their impersonal nature and the time and effort needed to complete open-ended questionnaires. As a data capture tool it may not be as robust and spontaneous as interviews, but the questionnaires returned did produce concentrated, quality information as respondents were focussed on answering the question in a detailed, and succinct, manner.

Capturing the views of patients who were not engaged in the empowerment paradigm did not enter the remit of the study, but it was felt that accessing the views of irregular attendees of the group was important. The Group Leader believed that irregular attendees would be comprised of those with poor access (due to employment or distance to travel), poor mobility and those disillusioned with the group and services they received. These issues of accessibility and appropriateness of the empowerment approach to T2D have been raised by commentators at the theoretical level (Asimakopoulou, 2007 and Redman, 2007 and Mol, 2007), but rarely captured in studies of experiences of T2D empowerment. It was felt that capturing these group members was important for exploring both the aims and objectives of the study, as well as to increase the heterogenity of the sample. Hence, alongside the initial introductory letter for the research (sent to all group members and professionals associated to the group) a qualitative questionnaire - which followed the question format of the respective one-to-one interviews – was enclosed.

This qualitative questionnaire format is rarely used in T2D qualitative studies – rather open questions are usually used in surveys to complement quantitative responses (Bowling, 2002). This is perhaps due to the limitations of qualitative questionnaires as a data collection method. The main limitation of the method is that qualitative questionnaires are impersonal, and easy for recipients to misplace or ignore - leading to a low response rate (Bowling, 2002). Equally, responding in writing to open-ended questions requires more effort and forethought than closed survey questions or interviews, and as such, are more demanding of respondents.
and, hence, likely to be limited by the respondents’ willingness to provide explanation. As such, it may also be the case that those disillusioned or unable to access the group are also less likely to fill in an open-ended questionnaire. It was felt, however, that this data-collection method would be a useful supplementary or introductory method, rather than ‘core’ method of data collection in this study.

2.3.5. Personal Information

All patient-participants, regardless of the data-collection method they chose to participate with, were asked to fill in a short ‘tick box’ questionnaire on socio-demographic information – asking questions on age; gender; marital status; ethnicity; educational qualifications; and number of people in the household as well as the household income. Participants were also asked how long they had been living with T2D – all these variables were derived from key themes identified in the initial literature review. At this stage, the main purpose of gathering this personal data was to assess the heterogeneity of the sample. During the analysis stage this background information was also applied to the codes developed to explore the role of standard sociological variables may play in these themes. As the data was also anonymized, the same patient-participant numbers assigned to the transcripts were also assigned to socio-demographic information. Healthcare professionals were asked to give details of their professional role and role in managing T2D.

2.4. Data Analysis

The data in this study were analysed using Framework Analysis developed by the National Centre for Social Research, which has become popular method of analysis in health-related studies (Ritchie et al, 2006b). The approach was chosen as it provides systematic and visible stages to the data analysis process (Spencer et al., 2006). The nature of this study is exploratory, and thus lends itself to a thematic analysis approach - a method for identifying, analysing and reporting patterns (themes) within data (Braun and Clarke, 2006). As the study,
had a realist epistemology, and wished to identify social-mitigating factors, an ideographic phenomenological approach, such as Interpretative Phenomenological Analysis, was not suitable. Rather, thematically analysing the data allowed for realist interpretation. The study employed a heterogeneous sampling method, used mixed data collection, and involved looking at sub-groups (healthcare professional and patient-related data). Thus, the data analysis process required a system that enabled clear tracking of these constituent data groups (different groups and data collection methods), as well as ways of synthesising these data groups. *Framework* is a method utilised within thematic analysis which facilitates rigorous and transparent data management and can be applied in an exploratory, inductive fashion (Ritchie et al., 2006b). One common misconception of Framework is that the approach is deductive, and that themes are coded in accordance to an a priori thematic framework (see for example: NIHR, Lacey and Luff, 2009). However, the approach is descriptive – not prescriptive – and offers a series of stages in data analysis which are amenable to both inductive and deductive modes of inquiry using thematic analysis. The approach involves five key stages: familiarization; identification of a provisional thematic framework; indexing; charting; and, mapping and interpretation.

**Familiarization:**

In the familiarization stage, the data was processed through transcription of the recorded and written material, and repeatedly read through line by line. Keeping the critical realist epistemological position, participants' accounts were treated as indicative of their lived reality whilst recognising that the meanings attached to experiences are mediated by social contexts (Willig, 2008). Significant and recurring themes and ideas were highlighted within the transcripts, then grouped under initial broad themes. Analysis was conducted sequentially in the order of patient focus groups, interviews, questionnaires followed by professional interviews to gradually build up the categorization of themes.
**Identifying the thematic framework:**

In this stage the researcher developed a provisional thematic framework identifying key issues or concepts within the broad themes – as well as any additional themes - from the data. How this data addressed the aims and objectives of the research was also considered. The end product of this stage was a framework in which all the data was indexed so that the data could be examined and referenced to themes through coding (Pope et al., 2000). To ensure rigour, transcripts were also read by the study supervisors and the thematic framework was developed keeping agreed themes, by negotiating and agreeing the content of themes, as well as the development of new themes (or sub-themes) where there was disagreement (Barbour, 2001). During data analysis, deviant case analysis was employed – where deviant cases are analysed to revise, broaden and confirm the patterns and themes in the data - this ensured refinement of the emerging findings (Pope et al, 2000). This process occurred recursively throughout the analysis.

**Indexing:**

During the indexing process, the researcher applied the index of the thematic framework to the data. This was done through numbering the theme on the transcript and annotating where codes or passages of text crossed over themes. Coding sheets were used whereby the themes were indexed for each transcript. This assisted with the charting process.

**Charting:**

Charting involved rearranging the data and extending the thematic framework in light of the application of the data. Each theme was assigned charts containing all instances of the theme – where instances of the theme (i.e. quotes) were cut and pasted. A description of the relevance of the data to the theme, participant and source of data (to aid memory), was pasted onto each theme sheet. The method is designed to encourage critical distance from the data and reduce researcher bias (Spencer et al., 2006). Charting is a two-way process as data can
be read as thematic across all respondents or by case for each respondent across all themes. Thus, further selective coding (axial coding) between codes can be carried out in order to discover categories that are related across themes. This allowed the researcher to chart the data by the healthcare professional and patient categories, data collection method, as well as by the background data collected on patients. Hence, it was possible to group, and develop definitional elements (sub-theme) to the theme. For example, one theme that emerged from charting was ‘route to diagnosis’, where respondents took various routes to diagnosis e.g. screening or a diagnosis due to hospitalisation. This positioned each participant differently in relation to symptom status during diagnosis of the condition (another sub-theme in meaning the type of diagnosis initially leads to different responses to T2D diagnosis).

**Mapping and Interpretation:**

Here the researcher used the information generated from indexing to define concepts, map the range and nature of phenomena within and across themes, create typologies and find associations between themes with a view to providing explanations for the findings and generating theory (Pope et al., 2000). This process was influenced by the relationship between the original research objectives and the developing themes. To demonstrate, by tracking the above example of ‘routes to diagnosis’ leading to differently realised ramifications – it was possible to relate these ‘routes to diagnosis’ to experiences and perceptions of barriers and facilitators in T2D management which could then be contrasted with healthcare professionals’ perceived barriers and facilitators. Equally socio-demographic data relating to participants was explored in relation to the themes to see if any patterns occurs.

2.5. **Reflexivity, validity and reliability strategies**

Reflexivity is an important issue in qualitative research. Reflexivity is an awareness of the ways a researcher’s identity and background can impact upon data-collection and analysis.
The researcher was a middle class, middle aged white male with a background in social research, working in a socially diverse, deprived area with a T2D group comprised predominantly of older people. Although the researcher’s background was enabling in the context of healthcare professional interviews, there was a potential for both perceived and actual power differentials relating to class, age, ethnicity and gender with the patient participants. To minimise this, it was made clear to patient participants that the researcher was independent, not a healthcare professional nor employed by the NHS, and the treatment and services they received would not be affected by taking part in the study. So too, that it was their perception and experience that was sought. The researcher also received extensive training in qualitative data-collection. Equally, the critical realist framework promotes unity of theory, thus data sources are evaluated for contribution to knowledge rather than support of a single theory. In developing and applying the framework for analysis, the researcher drew from current debates on the definition of empowerment. As the researcher’s and supervisors’ own works in this area were included, epistemological reflexive monitoring (the unity of theory approach in critical realism) was employed to reduce bias in analysis (Willig, 2008).

Cresswell (2007) suggests eight strategies for validity and reliability which have been used by different qualitative researchers, advising that at least two are followed in any given study. These strategies are: 1) ‘prolonged engagement and persistent observation in the field’; 2) ‘triangulation’; 3) ‘peer review or debriefing’; 4) deviant case analysis; 5) ‘clarifying researcher bias from the outset of the study’; 6) ‘the researcher solicits participants’ views of the credibility of the findings and interpretations’; 7) ‘rich and thick description’ and 8) ‘external audits’.

The above strategies were considered in the research design phase to promote reliability and validity in data collection and analysis. The validity and reliability of the findings of the study are explored further in the discussion chapter (as outcomes). The descriptions presented
below are the *a priori strategies* put in place to ensure validity and reliability throughout the course of the study:

1) First, over the course of 5 months the researcher maintained attendance at group meetings and consulted with the Group Leader and a patient representative to ensure engagement with the field of research. The researcher also attended (by invite) Diabetes Partnership Network meetings (i.e. healthcare professionals) over the period. This ensured *prolonged engagement in the field*;

2) Secondly, the study design allowed for *triangulation* of data collection methods to ensure heterogeneity of the sample, and validation of the themes developed during the analysis stage through comparison of data across data collection methods.

3) *Peer reviewing* of the project occurred at the research protocol stage, and the project was subject to independent assessment by two examiners in the PhD upgrade process. The research also attained NHS ethical clearance. Publications form the study are also peer-reviewed.

4) As the study was exploratory, the study did not have a central hypothesis requiring refinement over the course of the research. However, the aim and objectives of the research informed all aspects of the research process. Also, during data analysis, *deviant case analysis* was employed – where deviant cases are analysed to revise, broaden and confirm the patterns and themes in the data (Pope et al, 2000; Lewis and Ritchie, 2006). This ensured refinement of the emerging findings (Pope et al, 2000; Lewis and Ritchie, 2006);

5) Group members’ input into the suitability of the research design was sought during the development of data collection methods. Emerging findings of the analysis were presented for both the professionals and patients in the study. Hence, *participants’ views of the findings of the research were built into the research design*;

6) The use of semi-structured interviews allowed for ‘*rich and thick’ description* to be gathered;
7) Creating processes that allowed for ‘external audit’ - such as transparent systems of data collection and analysis (e.g. anonymized transcription and adoption of Framework Analysis) - are a prerequisite of NHS ethical clearance, where data must be produced and archived in a transparent manner to facilitate external audit.

2.6. Ethical Considerations

The study was granted approval by an NHS Research Ethics Committee (Ref No: 06/Q0703/137) and was not subject to any stipulations. Overall, the research sought to be as ethically sound as possible through procedural means contained in the planning of data capture and management methods. Participants were informed that they could choose to join or leave the research at any point in the fieldwork process, although none did. In seeking informed consent from participants, invitations and other materials were accessible in terms of age, ability, language and culture (this has been practiced in all the forms and information sheets attached in the appendices). In terms of the focus groups and all one-to-one interviews the participants were told orally by the researcher about the consent process at the time, and written consent was attained from all participants. In the case of questionnaires the issue of consent was outlined in written form and signed consent acquired.
All materials made clear that the decision to take part was independent of the service they received or their status as a patient, practitioner or co-caring participant. All information and data on participants was anonymised, and participants were allowed to access the information held on them providing it did not breach confidentiality (in line with the Data Protection and Freedom of Information Acts). The varied sampling methods were outlined and clarified in first contact with primary participants to avoid confusion and allay fears of manipulation. Participants were also given opportunities to contribute to the format of the data collection method through open topics. The researcher was also available for any further queries during the fieldwork period, and the participants could contact the research supervisors and/or the Group Leader for any further information.
Chapter Three – Findings: Profile of participants & diagnosis of Type 2 Diabetes

Profile of participants and their perceptions, understanding and experiences of T2D diagnosis

Chapter headings:

Introduction

3.1. Profile of participants;

3.2. Patients’ perceptions, understanding and experiences of T2D diagnosis;

3.3. Healthcare professionals’ perceptions, understanding and experiences of T2D diagnosis;

3.4. Comparing and contrasting patients’ and healthcare professionals’ perceptions, understanding and experiences of T2D diagnosis.
Introduction

This chapter begins with a profile of the borough and the participation group where the research took place (section 3.1.). In this section the socio-demographic characteristics collected from patients who took part in the study, and recruitment to each data-collection method, are presented. The healthcare professionals sampled are also discussed. The section outlines how the sampling successfully achieved a heterogeneous sample of people living with T2D within the borough and a range of healthcare professionals.

The chapter then presents findings relating to patients’ and healthcare professionals’ perceptions, understanding and experiences of T2D diagnosis. Each section describing how the themes identified address the research questions:

The research questions in support of this aim sought:

1) What are patients’ and healthcare professionals’ perceptions, understanding and experiences of successful and unsuccessful (un/successful) T2D management?

2) What barriers and enablers do patients and healthcare professionals perceive, understand and experience in relation to managing T2D on a day-to-day basis?

A third section describes how the main findings relating the research questions 1 and 2 in the preceding sections on patients’ and healthcare professionals’ perspectives converge and diverge to compare and contrast their perspectives, thus answering the third research question:

3) What similarities and differences emerge in patients’ and professionals’ perceptions, understand and experiences of managing T2D on a day-to-day basis.
3.1. **Profile of Participants**

3.1.1. **Socio-demographic context of the London borough**

The Borough selected for the fieldwork hosted a diverse socio-economic population – incorporating wards ranked within the 10 per cent of the most deprived areas in the country, with adjacent wards being amongst some of the wealthiest in the country. The borough was characterized by further social diversity in terms of age of the population, with 12.4 per cent of the population aged over 65, above the London average of 11.8 per cent. Within the borough, 10,124 people (3.9 per cent of the population) were living with T2D in 2007, slightly above the national average of 3.7 per cent (DoH, 2007). Commensurate with national trends, the Borough’s T2D population were predominantly aged 60 and over (DoH, 2008).

At the time of the study, sixty-three per cent (63%) of the population in the borough were white, 26% from black ethnic backgrounds (including an established Caribbean community, and a more recent African community) and Asian groups made up another 4% - as compared to 71, 12 and 11 per cent average for the UK (respectively, DoH, 2008). As such, there was an under-representation of the Asian community in the borough when compared with the national average. This is significant as across the UK (at the time of the study), 20 per cent of the South Asian community and 17 per cent of the African-Caribbean community were living with T2D, a significant increase when contrasted to average prevalence of 3% in the general population.

3.1.2. **Profile of sample participants living with T2D**

In total thirty-seven (n=37) people living with and managing T2D took part in the study and were interviewed using mixed data-collection methods which patient participants chose themselves. In total, the participation group had a membership of 166 people living with T2D.
at the time of the study, meaning 22% of patients in the group took part in the study. A table of the socio-demographic characteristics of people who took part is given overleaf (Table 1).
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<td>8%</td>
</tr>
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<td>£ 10 001-15 000</td>
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<td>17%</td>
</tr>
<tr>
<td>£ 15 001-21 000</td>
<td>9</td>
<td>24%</td>
</tr>
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<td>£ 21 001-28 000</td>
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<td>£ 28 000-36 000</td>
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</tr>
<tr>
<td>£ 36 001-45 000</td>
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<td>3%</td>
</tr>
<tr>
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<td>16%</td>
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<th>Time since diagnosis</th>
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<th>Percentage of sample</th>
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<tr>
<td>6 months</td>
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<td>8%</td>
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<tr>
<td>6-12 months</td>
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<td>27%</td>
</tr>
<tr>
<td>≥ 5 years</td>
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<th>Self-management Activity</th>
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<th>Percentage of sample</th>
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</thead>
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<td>Diet control only</td>
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<td>19%</td>
</tr>
<tr>
<td>Oral Medication</td>
<td>12</td>
<td>32%</td>
</tr>
<tr>
<td>Insulin Dependent</td>
<td>6</td>
<td>27%</td>
</tr>
<tr>
<td>No data provided</td>
<td>4</td>
<td>27%</td>
</tr>
</tbody>
</table>

Table 1: Socio-demographic and diabetic characteristics of sample
In the sample, women outnumbered men by 21 (57%) to 16 (43%). Participants reflected the ethnic make-up of the area, with the majority (n=24; 65%) of participants being white UK citizens. However, Asian participants were under-represented; this may be partially due to the low prevalence of Asian communities in the Borough. The majority of participants (n=27; 74%) sampled were retired older people (aged 60+). T2D tends to have a later age of onset across the whole population (Diabetes UK, 2010) meaning it was expected that older people would dominate the sample.

The sampling methods also caught a diverse range of living arrangements. Many participants were married and none reported co-habiting. Participants who also reported in interview as having spouses who had died, or were divorced, reported themselves as single, rather than ticking the widowed or divorced options (qualitatively realised). Of those who did report themselves widowed (n=4; 10%) all were female. The largest sub-group sampled was married males (n=12; 32%) who frequently attended the group with their wives. Two male participants reported (qualitatively) being gay.

Levels of educational attainment reflected the diversity of the area. The majority of participants (19; 50%) recruited were educated to secondary school level only, with three (n=3; 8%) participants reported that they had left education sometime during primary school. Many other participants had vocational, professional and university qualifications (n=14 in total; 38%). Patient participants with higher educational attainment also reported higher incomes, and those on lower incomes reported lower levels of educational attainment.

The sampling method also successfully captured people from varying socio-economic backgrounds. Only six (n=6; 16%) participants were living above the average (mean) income for households in 2007 of £23,140 per annum (Institute of Fiscal Studies:
seven (n=7; 19%) participants lived on less than £10,000 a year, four (n=4) of which reported living on below £6000 per annum. Income was also the most commonly unanswered question on the socio-demographic questionnaire (n=6; 16%). The sampling method also successfully captured variation in the time people had been living with T2D. The participants were also asked to discuss any co-morbidities they had in their interviews, seventeen (N=17, 46%) reported living with comorbidities. Illnesses reported included lupus, AIDS, hepatitis B, arthritis, cancer and cardio-vascular disease. Although it may be the case that more patients had comorbidities they did not mention or were undiagnosed. As we can see the sampling strategy successfully captured the group most likely to be living with T2D (older people 60+); and produced a heterogeneous sample of people living with T2D with regards to living arrangements, education, annual income, time since diagnosis and severity of the condition.

3.1.3. Profile of healthcare professionals

As noted, sampling through a T2D Participation Group offered access to a group of healthcare professionals associated with the patient group, and membership of the Participation Group by healthcare professionals demonstrated support of the purported aim of ‘empowering people living with T2D’. In total 10 healthcare professionals were recruited from a variety of occupational backgrounds:
<table>
<thead>
<tr>
<th>Role in T2D management</th>
<th>Number of Participants:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes Specialist Nurse</td>
<td>3</td>
</tr>
<tr>
<td>Diabetic Foot Care</td>
<td>1</td>
</tr>
<tr>
<td>Health Participation Officer</td>
<td>1</td>
</tr>
<tr>
<td>General Practitioner</td>
<td>2</td>
</tr>
<tr>
<td>Specialist consultant</td>
<td>2</td>
</tr>
<tr>
<td>Nurse Practitioner (at GP Surgery)</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 2: Healthcare professional participants by role and number participating

### 3.1.4. Recruitment to data collection method

A total of ten (n=10) healthcare professional interviews were conducted. In order to increase participation by patient participants, potential participants were given the choice of taking part through a range of data collection methods, and to participate through more than one format. Potential patient participants could choose between focus groups (and/or), qualitative questionnaires (and/or), one-to-one interviews. In order to collect rich, detailed information, healthcare professionals could take part in semi-structured one-to-one interviews. In total thirty-seven (n=37) members of the participation group were recruited as participants from a potential sample of n=166 group members (22% response rate), and were interviewed using focus groups, semi-structured interviews and qualitative questionnaires. In terms of recruitment to data-collection method within the patient sample, twenty-five (n=25) one-to-one interviews were conducted, 6 questionnaires were returned and 11 people attended 3 focus groups (n=3,3,5 attendees). Only five (n=5) participants participated in more than one
method; one questionnaire participant called the researcher to request a one-to-one interview, and 4 focus group participants went on to do one-to-one interviews.

3.1.5. **Guide to data presentation**

In the findings presented, quotes will be used throughout to illustrate themes. The quotes are followed by the abbreviations denoting patient (PT) and healthcare professional (HCP) participants. Patient interviews also show data collection method (interview = I, focus group = FG, questionnaire = Qn) e.g. PTI, PTFG and PTQn. A participant number (e.g. PTI#2), page (P.) and line (L.) numbers are also given for all quotes. This allows quotes to be traced back to the original transcript e.g. PTI #2, P.1:L1. For patient (PT) participants, gender is also given, i.e. (m) or (f), to allow the reader to develop a mental image of the participants. Where quotes from caregivers are given, this is highlighted within the patient participant’s transcript – as all interviews with carers were co-interviews. Themes within the data presented are identified by number and sub-themes by letter.
3.2 *Patients’ perceptions, understanding and experiences of T2D diagnosis*

Interviews, focus groups and questionnaires started with some general questions about diagnosis and the process that led to receiving a diagnosis of T2D. Three main themes were found in relation to patients’ accounts of diagnosis these were:

1) Route to diagnosis (e.g. screening or hospitalisation);

2) Symptom status during diagnosis; and

3) Response to the physical manifestations of T2D.

The first theme of *route to diagnosis* highlighted four distinct sub-themes reflecting different experiences of T2D detection and diagnosis, these were:

a) Symptom onset and self-referral;

b) Acute onset/hospitalisation diagnoses;

c) Screening diagnoses; and

d) Monitoring of a pre-existing condition or a dual diagnoses.

The route through which patients’ reached a diagnosis had implications for the barriers and enablers that they experienced.

In the second theme of *symptom status during diagnosis*, patients’ awareness and experiences of managing symptoms at the time of diagnosis are presented. Six sub-themes of symptom status were distilled from patient participants’ accounts:

a) Asymptomatic;

b) Awareness of symptoms and self-diagnosis;

c) Awareness of symptoms and self-referral at onset;

d) Uncertain of symptoms and delayed self-referral;

e) Apprehensive of symptoms and delayed self-referral;
f) Severe symptoms.

The final theme in patients’ accounts of diagnosis comprised descriptions of their responses to diagnosis. Some patients reported responding to the physical manifestations of T2D with shock (this was rare) or with uncertainty about how to respond to these manifestations. Equally, some patients felt the process of diagnosis facilitated better understanding of T2D and certainty as:

- Diagnosis explained the physical manifestations of T2D that patient participants had experienced; and
- For some participants diagnosed through screening, the tests involved in the screening process had demonstrated physical changes in the body (in the absence of symptoms).

Hence patients’ responses to diagnosis also highlight experiences which facilitated a more positive understanding of the manifestations of T2D and resolved the uncertainties patients experienced. As such they provide answers for the research question on enabling aspects of T2D management (research question 2).

3.2.1. Theme One: Routes to diagnosis

The patient participants who took part in the study were asked to recall - as clearly as possible - their experiences of diagnosis, and to discuss the impact of T2D diagnosis on their day-to-day lives. Patients were also asked what could have improved their experience of diagnosis. Patient participants discussed diagnosis as a process where T2D was detected, and subsequently diagnosed. All 37 participants identified to one of four main routes to diagnosis based on how T2D was detected or diagnosed – these were:

a) Symptom onset and self-referral;
b) Screening;
c) Onset of complications and/or hospitalisation relating to T2D;
d) Monitoring of a pre-existing condition or a dual diagnosis.

Sub-theme a: Symptom onset and self-referral route to diagnosis

Of the participants who took part in the study, twelve (n=12) received a diagnosis as a result of symptom onset and self-referral. The symptoms patient participants detected, prompted self-referral and eventual diagnosis. Symptoms followed the classic form of frequent urination, excessive thirst, tiredness and weight loss and/or gain. Some participants also reported prolonged sweats and feet pain as triggers to self-referral. Four ‘self-referring’ participants also self-diagnosed prior to attending the doctor for a formal diagnosis. Two of these patients self-diagnosed through working in the NHS and being able to test blood and urine, another patient participant’s daughter was a nurse who helped to diagnose T2D, and the remaining participant reported that he remembered the symptoms from caring for his mother with diabetes.

“I was a psychiatric nurse and I went to work and I didn’t feel well. To be honest I used to skip breakfast so I thought it was that. I should have noticed the symptoms, I had spoke to the doctor before but it was overlooked […] I just realised I had diabetes, so I checked […] I could have gone into a coma. All the doctor did was confirm it.”

PTI#20 (f) - P.1; L.10.

As we can see, this patient participant had also received an early misdiagnosis which acted as a barrier to diagnosis. Conversely, her knowledge of T2D, and access to testing equipment, also facilitated and enabled eventual diagnosis.

Sub-theme b: Screening diagnoses route

A further eleven (n=11) participants were informed of their diagnosis as a result of screening - or ‘M.O.T.s’ (as participants frequently referred to the screening process). Thus, the
screening route often engendered a unique set of barriers and enablers to managing T2D diagnosis. Instances of unsuccessful management by health services were also found.

Where symptoms were reported prior to screening these were often framed as having known something ‘wasn’t right’ but not having known what, or not having recognised the symptoms as ‘diabetes’. As such symptoms were retrospectively realised. The latter was common where T2D was reported as ‘in the family’ suggesting that, in some cases, patients were still able to explain away symptoms despite having familial experience.

“I should have spotted it really, my mother had it. But I’d put the weight loss and light-headed feeling down to age. But, of course, it was diabetes. I should have seen that.”

PTI#13 (m) - P.1; L.18.

Hence, one barrier to diagnosis within the screening route occurred where patients reported that they may have had symptoms before screening, but that they explained away these symptoms e.g. as ‘down to age’.

For some patient participants, the process of screening, i.e. when they obtained their results, demonstrated to them the effects of T2D when symptoms were largely absent.

“I knew that something was wrong with me but I didn’t know what it was. When I went to the hospital for some tests, I had to do blood and some liquid, and blow into something - and when they got the results they explained to me I had diabetes and what it is all about. The diabetes was happening in my body but I didn’t know.”

PTI#15(m) - P.1; L.16.

The process of screening itself facilitated these patients’ understanding of changes to their bodies which had led to their diagnosis, thus facilitating an understanding of their diagnosis.

Some participants diagnosed through screening (‘M.O.T’) reported that the delivery of their diagnosis acted as a barrier to understanding their diagnosis - as diagnosis was delivered inappropriately and with insufficient information:
“There wasn’t really any symptoms. I just went to have a check up and blood pressure and all that lot. [...] I got back the results, the lady from the surgery called me: ‘You have to come to see the doctor you’ve got diabetes.’ I don’t know her, is she a doctor? No. This isn’t right, can they do this? It’s my personal information.”

PTFG#2 Participant (ME) - P.6; L.9.

This informs the first research question relating to un/successful management of T2D, by giving an instance of unsuccessful T2D management, in this case by health services, at the time of diagnosis.

**Sub-theme c: Acute onset and hospitalisation diagnoses route**

In this third sub-theme, participants reported being diagnosed as the result of the sudden onset of a T2D complications and hospitalisation (n=5). Two of these participants reported that diagnosis was given when they were admitted to hospital with an ailment that was then discovered to be a diabetic complication, e.g. gout.

“I was taken to hospital. It was very sudden, I didn't know, it was just about two weeks, I started drinking a lot but I was in Kenya and Kenya was very hot, so I don't take it very seriously. I just thought it was because of the heat and I was running around and I was planning to come to visit my children, so I thought I was overdoing it, you know. And then finally I started going in and out of consciousness and I was taken to the hospital, and I was put in intensive care in Nairobi.”

PTI#3 (f) - P.1; L.16.

As we can see, although the participant had some awareness of signs of illness and changes to her body - these signs were dismissed in light of other things happening in her life. Again this route, reinforced a key barrier to T2D diagnosis - that the symptoms of T2D can be readily explained away in the day-to-day context of people’s lives, e.g. symptoms are explained away due to hot weather or ‘overdoing it’.

**Sub-theme d: Monitoring of a pre-existing condition or a dual diagnoses route**

The final sub-theme of ‘route to diagnosis’ comprised of people who received a dual diagnosis, or were diagnosed as a result of monitoring another illness (n=8). Illnesses reported included lupus, AIDS, hepatitis B, arthritis, cancer and cardio-vascular disease. These
participants frequently had no experience of T2D symptoms, or had only experienced T2D symptoms alongside symptoms of other conditions. For example, in discussing the onset of symptoms the participant below described how the symptoms of T2D were clustered together with HIV status:

“I knew I was ill but it wasn’t what I associated with diabetes and I should have recognised it - but I just thought it was a type of flu. I knew after a week it wasn’t flu but you would have thought the health professionals would have spotted it. But I got through it. [...] I am a diabetic because of the drugs given me for HIV, it turned me into a diabetic, that turned me into a person with high blood pressure, that gave me problems with cholesterol and now I have got angina. But they can all be kept under control with a bit of effort. [...]”

PTI#10 (m): P.1; L.20 / P.1; L.50

Conversely, some participants who reported a co-occurring condition at the time of diagnosis combined their understanding of T2D with the co-occurring illness in a way that made the two indistinguishable. As this newly-diagnosed patient participant described:

“I was having a lot of problems, which eventually got diagnosed mostly as prostate cancer, they included needing to pee fairly urgently, feeling rough, therefore eventually I did the un-male thing and went to the doctor [...] And first of all - blood samples - a couple of months later I got on to the alternate propositions -and confirmed as having both. The cancer and the diabetes. [...] A bloody nuisance but that so, basically as far as I can work out the symptoms are very much the same for both things. So I can't really complain too much about diabetes – I’m not sure if it is that!”

PTI#2 (m) - P.1; L.8.

Hence, we can see in this route to diagnosis also involved barriers to interpreting symptoms where patient participants had to tease out the symptoms of T2D from the effects of the co-occurring condition.

In overview, patients described diagnosis in terms of their ‘route to diagnosis’, and aspects of their experiences informed the research questions on barriers to, and facilitators of T2D
management (research question 2), and reports of un/successful management of T2D during the process of diagnosis (research question 1).

One patient reported misdiagnosis which acted as a healthcare professional-related barrier to a formal diagnosis of T2D. This barrier is possible across all routes to diagnosis. Some barriers reported were specific to patients’ routes to diagnosis. Patient participants with co-occurring conditions reported one barrier to T2D management relating to being unable to tease out symptoms specific to T2D. Another barrier, common in routes where symptoms were present, was the seemingly benign nature of T2D symptoms making it easy to explain some symptoms away, which delayed interpretation and self-referral.

Some patients with previous experience of T2D in their family saw experience of T2D as facilitating identification of symptoms, subsequent self-referral – and therefore enabling T2D diagnosis. Equally, access to diagnostic equipment facilitated self-diagnosis which later led to formal diagnosis.

Finally, it was found that some patients felt their diagnosis had been un/successfully managed, as some participants who received a diagnosis through screening described diagnosis as being poorly delivered.

3.2.2. Theme two: Symptom status during diagnosis

Routes to diagnosis engendered different experiences of symptoms, purely in terms of how the condition had progressed prior to detection or diagnosis. These ranged from asymptomatic, to mild, to some patients’ experiencing severe complications. Patients were either screened, hospitalised or referred themselves to health professionals for diagnosis based on their assessments of the symptoms, or for an existing condition. Six sub-themes of
symptom status were found based on the participants’ experiences of symptoms and the role the patient played in eventually being diagnosed by a healthcare professional:

a) Asymptomatic;
b) Awareness of symptoms and self-diagnosis;
c) Awareness of symptoms and self-referral at onset;
d) Uncertain of symptoms and delayed self-referral;
e) Apprehensive of symptoms and delayed self-referral;
f) Severe symptoms.

Each of these sub-themes is explored below.

**Sub-theme a: Asymptomatic**

This sub-theme incorporated patients who described themselves as asymptomatic at the time of diagnosis, as they were diagnosed with T2D through screening. As such, no self-referral to health services occurred and patients had little experience of symptoms during diagnosis.

“I went to the clinic for some tests, the annual tests where they test blood and so forth and it came out that I was diabetic, which was a surprise, as I had no previous symptoms.”

*PTI#5(m) - P.1; L.15.*

These patient participants often reported the process of screening itself as demonstrating to them that T2D had ‘occurred in the body’, as the quote above stated:

“The diabetes was happening in my body but I didn’t know.”

*PTI#15(m) - P.1; L.19.*

**Sub-theme b: Awareness of symptoms and self-diagnosis**
Patients described themselves as aware of their symptoms prior to diagnosis, but were not formally diagnosed with T2D, but were briefly self-diagnosed.

“I had spoke to the doctor before but it was overlooked. [...] I just realised I had diabetes, so I checked [...] All the doctor did was confirm it.”

PTI#20 (f) - P.1; L.12.

This patient participant reported having had symptoms and suspected they related to T2D. She had acknowledged these symptoms by self-referring to a healthcare professional. However, she initially did not receive a diagnosis of T2D when she visited her doctor. At this stage, she suspected that the symptoms were to T2D, but had no diagnosis. She later self-diagnosed which was then confirmed at a later date. As noted, four participants reported self-diagnosing.

Sub-theme c: Awareness of symptoms and self-referral at onset

Patient participants described themselves as aware of symptoms prior to diagnosis and were later diagnosed with T2D through self-referral to a healthcare professional. Patient participants described that they had symptoms prior to diagnosis but did not suspect T2D. Almost straight away, they acknowledged these symptoms by self-referral to a healthcare professional, after which they had received a diagnosis of T2D.

“I kept getting really tired, just tired and a bit thirsty. So I went to the doctor and they did some tests and there it was – ‘You’ve got diabetes’”

PTI#11 (f): P.1; L.10.

Sub-theme d: Uncertain of symptoms and delayed self-referral

Patient participants described themselves as aware of physical changes prior to diagnosis, but uncertain whether to ascribe these sensations the status of symptoms. Symptoms were easy to explain away, therefore, there were delays in self-referral and eventual T2D diagnosis.
“...I just thought it was a type of flu...”

PTI#10 (m): P.1; L.2.

In this manner, symptoms were also interpreted by patient participants as ‘not too serious’ or not prioritised.

“I just thought it was because I was overdoing at work, you know?”

PTI#5 (f) - P.1; L.21.

Following a visit to the doctor, a diagnosis was made at a later point. It is likely that in severe cases, this accelerated to diagnosis by hospitalisation.

**Sub-theme e: Apprehensive of symptoms and delayed self-referral**

A few patient participants described themselves as aware of physical changes, but feared potentially negative outcomes and therefore delayed self-referral and T2D eventual diagnosis. The symptoms were viewed as a potentially serious illness, or the effect/complications of another pre-existing condition. The actual existence and/or effects of the symptoms were then disavowed or assigned to a different pre-existing condition or event by the patient participant in fear of potentially negative outcomes. An example of this is given below – where the participant was newly diagnosed with T2D and was living with Lupus. She described her uncertainty about the status of some of the symptoms:

“Sometimes, the way I feel, I probably think I should go and tell the doctor that I’m feeling quite bad - and I sometimes do. But usually it just goes by itself, comes and goes, and I just can’t think about more tablets or injections - I’m not really up for that.”

PTI#9 (f) - P.1; L.38.

**Sub-theme f: Severe symptoms.**
One patient described her symptoms as being so severe at the point of diagnosis that she was no longer able to respond as the symptoms had affected her judgement. She was diagnosed through hospitalisation:

“I had a kind of thing in my brain that somebody wanted to kill me, maybe it was the many books I read, you know. And I became very uncooperative. And finally, well finally... they managed to put me under and treat me because -for the first few days - they could not come near me, I used to throw cups of tea at nurses and, and kicking the lab testing, you know.”

PTI#3 (f) - P.1; L.26.

This participant described a state where her symptoms were so advanced she did not have the cognitive ability to identify and respond to her symptoms appropriately.

In summary, this theme addresses the research question pertaining to barriers and facilitators to T2D management. One factor providing a barrier to patient self-referral (where symptoms were present) was that patient participants were easily able to explain away the symptoms of T2D. Patients described how their fear of negative outcomes, wider day-to-day commitments and, in some cases, co-occurring illness meant symptoms were disavowed or not acted on. These factors explained delays in self-referral. Also, in extreme cases another barrier to diagnosis may occur when the patient becomes unable to respond appropriately due to severe complications, particularly in the hospitalisation route. We can again see that knowledge and prior experience of T2D facilitated or enabled self-referral in the symptom-onset and self-referral route.

3.2.3. Theme three: Responses to diagnosis

Whereas the previous theme focused on how, and whether, awareness of symptoms led patients to self-refer for a professional diagnosis. This theme looks at the ways patients
responded directly to diagnosis. It was found that the degree to which receiving a diagnosis explained the physical manifestations of T2D, shaped the patient participants’ response to diagnosis, and initial confidence in managing the illness. Patients’ responses to diagnosis were characterised by either: 1) uncertainty about symptoms were to be identified and responded to; or 2) diagnosis as having clarified and addressed uncertainties patients had experienced prior to diagnosis. This theme, thus, addresses the research question examining barriers and enablers to managing T2D through the certainties and uncertainties patients’ experienced after formal diagnosis.

Only one participant described diagnosis as an emotional shock and then denial of diagnosis.

“They kept telling me that I’ve got it, and I kept denying that I’d got it, and then I suddenly thought I suppose I’d better go and see what they talk about, information and that. So I thought okay I’ll go and get some more information and see what its like[...] but I was just sitting there thinking I haven’t got it.”

PTI#9 (f) - P.4 ; L.45.

Hence, shock and denial responses to T2D diagnosis were rare in this sample. Rather, a few participants reported diagnosis as a ‘relief’ as it provided explanation to the uncertainties they had experienced when symptoms had emerged.

“I realised I was mortal. It was a real shot in the arm. It [diagnosis] explained why I had felt so dreadful”

PTI#13 (m) - P.3; L.1.

However, formal diagnosis was described largely as interpreting the diagnosis by how T2D had affected the body. Hence, the most common response patient participants’ described in relation to T2D diagnosis was the experience of uncertainty about how to manage the physical manifestations of T2D. Even after formal diagnosis, some patient participants’ described experiencing uncertainty about whether, or how, to respond to the physical manifestations of T2D. Patient participants described their responses as being characterised by uncertainty about a) what constituted a symptom (symptom uncertainty), as well as  b) the seriousness of
symptoms, and therefore whether the symptom warranted medical intervention or could be dealt with by the individual (response uncertainty) e.g.:

“[V]ery difficult because you can only know so much, you don’t know who to ring. Do I ring the GP, the on call doctor, someone at [the Hospital] or just get on with it. It could be anything”

PTI#25 (f) - P.1; L.21.

Participants who had a co-morbidity or dual diagnosis at the time of formal diagnosis also experienced symptom uncertainty, as they still found it difficult to distinguish between the symptoms of T2D and the co-occurring illness, and how to manage the co-occurring illnesses in conjunction with T2D:

So I can't really complain too much about diabetes – I’m not sure if it is that!”

PTI#2 (m) - P.1; L.15.

“I have asthma, blood pressure and glaucoma and I have got ...and something with the liver. Hepatitis, Hepatitis C. That is something recently, they just found it recently. And so many pills, and specialist for this, diabetes nurse. When I started first I feel funny, because there is so many pills to take and I feel so sick that I thought it was the tablets. I went to the doctor as well, Dr [Name], and said just wait and see, wait and see, and I need to go back in six months.”

PTI#6 (f) - P.1; L.38.

As patient participants had different symptom statuses at the point of formal diagnosis, it is also likely they have different levels of experiential knowledge and confidence in identifying and responding to symptoms at this time.

In overview we can see that cases of patients responding to diagnosis with shock and denial were rare in this sample. A few patient participants’ described experiencing uncertainty about how to respond to the physical manifestations of T2D even after formal diagnosis. In their accounts, patients reported uncertainties related to identifying and responding to symptoms after diagnosis, which acted as a barrier to effective management of symptoms at the time (informing research question 2). In some cases, patient participants framed diagnosis as a positive experience, as diagnosis clarified the uncertainties they had experienced as the
manifestations of T2D had taken hold. As such, for some patients, diagnosis clarified uncertainties that had developed with the onset of symptoms enabling treatment and management of T2D (again informing research question 2).
3.2.4. Overview of themes relating to patients’ experiences, understanding and perceptions of diagnosis

Some routes to diagnosis incorporated symptom statuses which shaped patients’ experience of self-referral. However, patient participants also reported different symptom statuses at the time of diagnosis which, in some cases, contributed to delays to self-referral. Equally, patient participants reported responding to formal diagnosis in different ways, and experiencing different types of certainty and uncertainty. These themes can be represented as a process, as follows (see table 3 overleaf):
Route to diagnosis-T2D was detected/diagnosed as a result of:

| Symptom onset and self-referral (n=12) | Symptom status: b (n=4) | 1. Potential for response/symptom uncertainty (pre-and post-diagnosis)  
2. Potential for diagnosis to resolve uncertainty by explaining the physical manifestations of T2D |
| Screening (‘M.O.T’) (n=12) | Symptom status: a | 1. Potential for response/symptom uncertainty (post-diagnosis)  
2. Potential for diagnosis to resolve uncertainty by explaining the physical manifestations of T2D |
| Onset of complications (and) hospitalisation relating to T2D (n=5) | Symptom status: c, d, e, & f | 1. Response/symptom uncertainty may contribute to late diagnosis  
2. Potential for severity to lead to inability to respond to physical manifestations of T2D |
| Monitoring of a pre-existing condition (n=5) or a dual diagnosis (n=3) | Symptom status: c, d, & e | 1. Potential for response/symptom uncertainty due to co-occurrence of illness;  
2. Potential for diagnosis to resolve uncertainty by explaining physical manifestations of T2D.  
3. T2D symptoms are seen as separate to co-occurring condition and managed as such (pre- or post-diagnosis)  
4. T2D symptoms are seen as related to, and managed as, part of the co-occurring condition (pre- or post-diagnosis) |

*Symptom status key: (a) Asymptomatic; (b) Awareness of symptoms and self-diagnosis; (c) Awareness of symptoms and self-referral at onset; (d) Uncertain of symptoms and delayed self-referral; (e) Apprehensive of symptoms and delayed self-referral; (f) Severe symptoms.

Table 3: Route to diagnosis, with reported statuses of symptoms and patient responses

To summarise, we can see that these themes informed the research questions in multiple ways. In total six barriers were identified by patients in relation to patients’ experiences of T2D diagnosis. Two barriers to T2D diagnosis were specific to route to diagnosis:
1) The presence of co-morbidity complicated the identification of T2D symptoms for those who received a dual diagnosis or diagnosis through monitoring another condition;

2) In the hospitalisation route to diagnosis one patient reported T2D that their symptoms had become so severe that she was unable to respond to them.

Another barrier identified to achieving a T2D diagnosis, but with the potential to act across all routes, was misdiagnosis.

The second theme honed down on the experiences of symptoms leading up to the point of formal diagnosis and found barriers to self-referral which contributed to delays in diagnosis. Patient participants described how their fear of negative outcomes, wider day-to-day commitments and, in some cases, co-occurring illness meant symptoms were frequently disavowed or not acted on.

Only one participant reported the barrier of being shocked by and subsequently denying their diagnosis. It was more common for patients to experience uncertainty in relation to identifying and responding to symptoms which acted as a barrier to their understanding of managing symptoms following formal diagnosis (symptom and response uncertainty).

In total three enablers were identified by patients in relation to patients’ experiences of T2D diagnosis.

It was found that patients with previous experience of T2D in their family saw this as facilitating identification of symptoms and subsequent self-referral – and therefore enabling T2D diagnosis. However, some participants were able to explain symptoms away despite familial experiences of T2D. Equally, 2) access to diagnostic equipment facilitated self-diagnosis which eventually led to formal diagnosis. It was found that 3) formal diagnosis lessened the uncertainties that a few patients’ had experienced in identifying and responding
to symptoms which encouraged patients to look for ways to manage the physical manifestations of T2D.

One example of poor management by healthcare professionals was found. Some patients felt their diagnosis had been un/successfully managed - these participants had all received a diagnosis through screening and had described their diagnosis as being poorly delivered.

Hence, patients reported barriers to successful management of diagnosis as predominantly T2D-related: i.e. symptoms can be explained away easily or confused with other symptoms which delayed self-referral, or T2D can be so severe its manifestations affect the patients’ capacity to respond. The former can be exacerbated where there are co-morbidities at the time of diagnosis. Self-reported patient-related barriers to the successful management of diagnosis were found, such as uncertainty and apprehension which led to delayed self-referral, denial of diagnosis and confusion about how to self-manage. Equally, it was found that previous knowledge and experience of T2D and access to testing equipment amongst patient participants facilitated self-referral for diagnosis (acting as enabler to T2D diagnosis). At the healthcare professional/health service level misdiagnosis was reported as a barrier to diagnosis, and instances of poor management of diagnosis were given. On the other hand, (well-managed) diagnosis was seen by some patients as demonstrating to them the effects of T2D (in screening diagnosis) and explaining the symptoms they experienced.
3.3. **Healthcare professionals’ experiences, understanding and perceptions of T2D diagnosis**

Healthcare professionals were asked how they approached T2D diagnosis. This aimed to address research questions relating to exploring healthcare professionals’ perceptions, understanding and experiences of what constitutes successful and unsuccessful (un/successful) T2D management and identifying barriers and enablers (at the diagnosis stage).

The three main themes distilled from analysing the accounts of healthcare professionals all related to techniques they used to successfully managing T2D diagnosis with patients, these were:

1) Finding a trigger for patient action;
2) Encouraging reflection in light of clinically-recommended behaviours; and
3) Outlining the potential consequences of T2D and creating options for patients.

In discussing these techniques, healthcare professionals portrayed the ideal type of diagnosis as a starting point for promoting patient self-management. This meant healthcare professionals discussed how diagnosis should be successfully managed and gave examples. Hence, unsuccessful management was bracketed out of healthcare professionals’ accounts; rather barriers to successful management were reported. These barriers were seen portrayed as largely patient-related.

### 3.3.1. Theme One: Finding a trigger to action
All the healthcare professionals interviewed acknowledged that diagnosis was a significant, but difficult, time for patients.

“We have to ask users of diabetes services - how could it be improved when you are first diagnosed with diabetes? How could your experience have been improved? What could we have done? How could have made it easier for you? Less frightening? you know”

HCP#1 - P.1; L.41.

In their accounts of managing diagnosis, healthcare professionals described asking patients their concerns. This was done to assess what kind of information patients wanted, as well as how much information the patient would like. Healthcare professionals believed that this made it possible to trigger the patient to realise what they could personally do to address their T2D concerns (by adopting self-managing behaviours).

“In consultation my aim will be to get the patient to take things on board .... Because I think, that in theory starting to manage your own illness should be terribly easy. But it is not - because of human nature. So part of diagnosis is to try and figure out what the triggers are for that person - in that moment in time, so I do have to assess how much information people want. This is what I ask first. What can you actually manage?”

HCP#7 - P.4; L.28.

Tailoring information provision to promote clinically-recommended behaviours was seen as the best way to trigger patients to act. Hence, finding a trigger for action, and assessing how much information patients required was seen by healthcare professionals to enable better management of T2D by the patient at the time of diagnosis. The barriers discussed related to how much information patients were able to absorb at diagnosis. Conversely some healthcare professionals reported the barrier of patients not being ready to engage with clinically-recommended behaviours – and as resisting the trigger:

“But when you are told, you know, you have this condition you will have to manage for the rest of your life. And then you... You don’t really want to take
that onboard. If you imagine that you feel, well, like shit, you don’t want to invest time and effort into something that feels shit.”

HCP#6 - P4; L26.

Therefore, barriers to diagnosis are seen portrayed in terms of how willing or able patients were to absorb, and respond to, the initial triggers to self-manage.

“[S]ome people get powered up and motivated and come in with reams of stuff from the internet. They know what their blood should be and they are really taking charge of themselves. Sometimes it is support, how people are connected to services. But I have had people who don’t connect, they don’t feel sick so they don’t get the message. We give them what the current guidelines are for what their blood sugar levels should be in the long term and short term – Then we see them at the next appointment and nothing has changed.”

HCP#8 – P2; L35.

As we can see, ‘taking charge’ of T2D was seen by healthcare professionals as patients grasping the information given and placing it in the context of their wider concerns. This was seen as facilitating patients’ understanding of what was required to self-manage T2D.

3.3.2. Theme Two: Encouraging reflection in light of clinically-recommended behaviours

Healthcare professionals then also described introducing the recommended behaviours of T2D self-management at the time of diagnosis:

“We’d[...] talk to them about different ways that they could, say, monitor [their blood sugar] - or so that they could look at, you know sort of just having a time that they relax a little bit because sometimes you can get very anxious [...] but at the end of the day [...] I will tell them...] the only way you really know how your diabetes is, is if you monitor, so if you don’t monitor at all then you won't know how your diabetes is. Then the diabetes will be in charge. So it’s giving people the information that we have so that they understand it and then they can make a decision themselves as to what they want to do with that information.”
Hence, healthcare professionals made patients mindful of the importance of clinical-recommended behaviours.

“So you sure make someone is making the right choices, knows what they are looking for with their illness, someone who knows what they’re preferences are and how to go about finding help when they need it. Someone who knows their condition and knows what signs to look for.”

HCP#8 – P.3; L.27.

Thus, adopting clinically-recommended behaviours were seen as promoting successful long-term self-management, and facilitated self-directed help- and information-seeking in patients.

3.3.3. Theme Three: Outlining the potential consequences of T2D and creating options for patients

Healthcare professionals described outlining to patients the benefits of responding to T2D diagnosis as early as possible, as well as the potential consequences of T2D and the consequences of inaction to their patients. The healthcare professional below outlined how she explained the ‘costs and benefits’ of self-managing and created options for patients at the diagnosis stage:

“If you can self-manage your diabetes, you can adjust your medication or you can manage your diabetes yourself, so that your blood glucose levels and everything are under control to reduce your risk of complications. If you’re always relying on a healthcare professional to manage it for you, it’s not going to be managed as often, so there’s going to be great periods where your sugar levels might be very high and nothing is being done about it, which can make you feel very unwell if your sugar levels are too high. So it’s giving them the tools to manage their condition.”
Hence, having assessed of how much information patients were able to deal with, and encouraging reflection, healthcare professionals gave options which showed patients how T2D could be successfully managed, and the potential consequences of inaction. Healthcare professionals also reported diagnosis as a consultative process, where focus was on options for future behaviour, and on ‘skilling’ patients – mainly through information giving - to successfully self-manage T2D. Healthcare professionals equated patients’ willingness to engage with these options as barriers and facilitators of a successful diagnosis.

“They say: ‘Well what should I do about my blood sugar?’ And I say: ‘Well let’s sit down and have a look, What do you think you can do?’ ‘BUT I’M ASKING YOU!’ They don’t except they have a choice to make. [...]But people have to decide where diabetes fits in their life. Some people their whole life revolves around it other people are thinking ‘well I am still me, and I happen to have diabetes’ and sort of get on with it. Other people put it in a cupboard - at the back.”

HCP#8 - P.2; L.35.

“It’s great because people have got the choice that if they want to be completely in charge they can.”

HCP#8 - P.6; L.2.

Hence, barriers and enablers to successful T2D management at the time of diagnosis were couched by healthcare professionals in the patients’ willingness to respond to, and prioritise T2D diagnosis in terms of clinically recommended behaviours (often reported as ‘control’).

“Of course you get people who don’t want to change. They’re in denial, or they have chaotic lives – whatever the barrier is and they never ...Well, they struggle to take control and the diabetes takes over”

HCP#6 - P.2; L.10.

Or as noted in a previous quote:

“Some people their whole life revolves around it other people are thinking ‘well I am still me, and I happen to have diabetes’ and sort of get on with it. Other people put it in a cupboard - at the back.”

HCP#8 - P.2; L.38.
3.3.4 Overview of themes relating to healthcare professionals’ experiences, understanding and perceptions of diagnosis

Three interrelated themes were found in healthcare professionals' accounts of managing T2D diagnosis. These themes were primarily techniques to promote successful patient self-management at the point of diagnosis.

Figure 4: Themes from healthcare professionals’ accounts of diagnosis

These themes answer the research questions by distilling healthcare professionals’ experiences, understandings and perceptions of successful management of diagnosis. Also, in discussing these techniques as ideal ways to promote patient self-management at the time of
diagnosis, healthcare professionals reported *patients’ willingness and ability to take part in these processes* as key to understanding barriers and enablers to T2D management.

Promoting successful T2D management during diagnosis was reported by healthcare professionals. This involved listening to patients’ concerns to find a trigger for action and tailoring information in light of this, as well as encouraging patients to reflect on fitting clinically-recommended behaviours into their lives.

Healthcare professionals perceived barriers or enablers to the successful management of diagnosis as mainly relating to patients’ resistance or willingness to absorb and act on information and clinically-recommended behaviours. Healthcare professionals also discussed the potential consequences of T2D with patients to encourage them to ‘choose’ the (successful) self-management option. In this case, barriers and enablers to successful management were equated with patients’ willingness, and sometimes ability, to prioritise the clinically recommended behaviours of T2D self-management to prevent the consequences of T2D (see figure overleaf):
Healthcare professional promotes successful management of diagnosis by:

<table>
<thead>
<tr>
<th>Finding a trigger to action</th>
<th>Patient-related barrier reported:</th>
<th>Patient-related enabler reported:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patients’ unwillingness to absorb information</td>
<td>Patients’ willingness to take information on board facilitates identification of their needs.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Encouraging reflection in light of clinically-recommended behaviours</th>
<th>Patient-related barrier reported:</th>
<th>Patient-related enabler reported:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patients do not respond to information they have been given.</td>
<td>Patients integrate information into their responses to T2D.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outlining the potential consequences of T2D and creating options for patients</th>
<th>Patient-related barrier reported:</th>
<th>Patient-related enabler reported:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>‘Denial’</td>
<td>Patients’ choosing to prioritize clinically recommended behaviours</td>
</tr>
<tr>
<td></td>
<td>Patients’ choosing to not prioritise clinically recommended behaviours</td>
<td></td>
</tr>
</tbody>
</table>

Table 4: Healthcare professionals’ perceptions of successfully managing T2D and perceived barriers and enablers by theme
3.4. Comparing and contrasting patients’ and healthcare professionals’ experiences, understanding and perceptions of T2D diagnosis

In addressing the final research question, we compare and contrast patients’ and healthcare professionals’ accounts of their experiences, understanding and perceptions of T2D diagnosis, and highlight ‘divergences’ and ‘convergences’ that occur. Equally, some aspects of diagnosis identified by this aspect of the analysis were found to remain specific concerns to each group of participants and are reported as ‘healthcare professional and patient-specific concerns’.

_Divergence:_

Starting with the research question on barriers and enablers to the management of T2D diagnosis, we can see divergence in the barriers and enablers experienced by patients and healthcare professionals. Patients reported barriers to diagnosis relating to interpreting and responding to T2D-related symptoms both pre- and post-diagnosis. T2D symptoms were reported as being easy to ignore as they were experienced as mundane, day-to-day physical sensations or conflated with the symptoms of other conditions. As a result of this, patients reported delays in self-referral and, post-diagnosis, uncertainty about whether, and how, to respond to physical manifestations of T2D, i.e. they were T2D-related.

Healthcare professionals, on the other hand, saw diagnosis as the starting point for self-management, and listened to patients’ concerns and offered information on clinically-recommended behaviours to promote the self-management ‘options’. As such, barriers to successfully managing diagnosis were seen to be patient-related. The main barriers identified related to patients’ willingness to act in a fashion deemed to be self-managing to avoid T2D-related consequences (post-diagnosis). Therefore, there appears to be a divergence in the patients’ and healthcare professionals’ experiences, understanding and perceptions of barriers to managing T2D diagnosis. Healthcare professionals’ emphasis on barriers being related to
patients’ resistance in choosing and adopting self-management behaviours is a stark contrast to patients’ accounts of uncertainty about interpreting and responding to symptoms. Patients sought to discover the nature and cause of T2D symptoms, whilst healthcare professionals sought to outline the long-term gains of managing these symptoms. It is, however, unclear as to whether it is possible that patient uncertainty was being interpreted by healthcare professionals as unwillingness to adopt self-management behaviour. But where these contrasting viewpoints occur, it is likely to undermine therapeutic aspects of the relationship.

In contrasting these perspectives, there is also a mismatch between the timeframes used by healthcare professionals and patients to interpret diagnosis. The mismatch is illustrated by the types of barrier reported by each group. Barriers patients reported were related to the symptoms and severity of T2D itself, which shaped patients’ capacity to respond and self-refer during diagnosis. These barriers were frequently unique to the patients’ route to diagnosis, i.e. their experiences where shaped by immediate circumstances. As such, the barriers to diagnosis patients experienced related to the immediate uncertainties experienced in the process of diagnosis itself, and whether or not these were resolved during the process. Healthcare professionals felt T2D diagnosis was best addressed through outlining clinically recommended behaviours, and promoting self-management to prevent future T2D complications. Emphasis here was post-diagnosis, and often long-term with the gap being plugged by information giving and time to reflect.

Congruence:

A few patients reported formal diagnosis by a healthcare professional as having resolved the anxieties they experienced during symptom onset or having demonstrated the effects of T2D in those who were asymptomatic. This suggests that in some cases, clarity of diagnosis, information and evidence about T2D during diagnosis can ameliorate uncertainty and enable a clear understanding of the condition. This was congruent with healthcare professionals’
assertions that successful management involved tailoring information to patients’ concerns during diagnosis.

Equally, shock and denial of diagnosis were discussed by both sets of participants. Although ‘denial’ was congruent in both sets of accounts, it was found to be an uncommon response to diagnosis amongst patient participants. It was, however, frequently cited as a barrier to accepting the consequences of T2D and moving towards self-management by healthcare professionals.

*Healthcare professional and patient-specific concerns:*

The different routes that patients took to diagnosis involved different experiences of symptoms and severity at the time of diagnosis. Patients also reported previous familial experiences of T2D, and having access to testing which allowed for self-diagnosis of T2D and enabled self-referral. Overall, healthcare professionals placed emphasis on enabling self-management at the point of diagnosis, whereas patients largely described the process of diagnosis through their route to diagnosis. Healthcare professionals gave no examples of how patients’ experiences of symptoms, the severity of T2D and past experiences of T2D shaped their approach to diagnosis. Equally, patients rarely discussed their expectations of healthcare professionals in relation to diagnosis except where misdiagnosis or poor management of diagnosis had occurred.

By comparing and contrasting patients’ and healthcare professionals’ accounts of diagnosis it was found that their experiences, understanding and perception diverged and converged during diagnosis. Patients and healthcare professionals experienced different barriers relating to diagnosis and viewed diagnosis using different timeframes, i.e. in the immediate and long-term (resp.). There was some congruence in reports that providing information and evidence facilitated better understanding and acceptance of T2D in patients, with poor management of
T2D diagnosis being seen as poor management of diagnosis. There also appears to be aspects of diagnosis unique to both sets of participants.
Chapter Four – Findings: Adaption to living with Type 2 Diabetes

Patient and healthcare professional participants’ perceptions, understanding and experiences of T2D diagnosis.

Chapter headings:

Introduction

4.1. Healthcare professional participants’ perceptions, understanding and experiences of adapting to living with T2D;

4.2. Patient participants’ perceptions, understanding and experiences of adapting to living with T2D;

4.3. Comparing and contrasting patient and healthcare professional participants’ perceptions, understanding and experiences of T2D diagnosis.
Introduction

This section looks mainly at patients’ experiences and perceptions of adapting to living with T2D. This is because, as with diagnosis above, healthcare professionals saw their role in the adaption process as listening to patient concerns, imparting information to address concerns and triggering the process of self-management of T2D. Healthcare professionals’ accounts reported adaption as a period of adjustment following diagnosis and therefore, their perceptions of the barriers and enablers and un/successful management were conflated with their accounts of managing diagnosis (as reported above). Hence, only a brief subsection below gives examples of how healthcare professionals viewed adaption (section 4.1).

Patient participants were asked to recall and describe how their life had changed since diagnosis, and what impact T2D had on their lives. Patient participants made changes to areas of their lives in light of their nascent experiences of T2D, and subsection 4.2 (below) outlines the four common themes identified (areas of impact) where this occurred. These were:

1) Developing a causation account of T2D;
2) Adjusting time and resources to adapt to living with T2D;
3) Adjusting social relationships to adapt to living with T2D;
4) Adjusting relationships with healthcare professionals and use of health services to adapt to living with T2D.

As we can see these themes were developed with the epistemological stance informing the approach to analysis. Each theme highlights how patients mediate or strike a balance between a personal concern, i.e. living with T2D and associated needs, and factors in their social contexts, i.e. use of time, health services and effect on relationships. Each of these themes are discussed in turn below, and perceptions, understanding and experiences informing 1) un/successful T2D management and 2) barriers/enablers to T2D management – are highlighted. To examine the third research question, subsection 4.3. compares and contrasts
patients’ and professionals’ perceptions, understanding and experiences of the adaption process in T2D management.

4.1. **Healthcare professionals’ perceptions, understanding and experiences of adapting to living with T2D**

During their interviews, healthcare professionals were asked to describe their experiences of helping patients adapt to living with T2D. Generally, healthcare professionals discussed the physiological consequences of T2D and described how patient-led behaviour change could minimise risks and complications.

“Usually the result of lifestyle factors [...] But patients don’t really see the seriousness of lack of insulin effectiveness, they don’t see the effects on blood pressure, and that as the blood thickens your risks for micro-vascular and macro-vascular complications can soar. So tight control of blood sugars is essential, so patients need to take responsibility and own the condition.”

*HCP#7 - P.3; L.17*

Healthcare professionals again described facilitating self-management by advising patients how they could fit clinically-recommended behaviours within their day-to-day lives, i.e. how patients could learn to self-manage T2D.

“It won’t always be the same thing – but what are the issues or constraints that are stopping them [patients] from achieving what they want to do. Side effects of medicines, maybe they don’t want to take tablets, or a busy life, a newborn blah blah blah [...] The bottom line is to keep the diabetes well controlled by adapting it to what they feel they can do – Avoid complications and minimise risk to patients.”

*HCP#7 - P.8; L.6.*

On the whole, healthcare professionals used their discussion of adaption as an opportunity to describe how they actively attempted to understand the issues patients faced in self-managing T2D, and find ways patients could overcome them:
“If you want somebody to make a change, they want to make it - it's got to be possible for them to make it. So exercise, for example: Where do you go? Where do you do the exercise? What kind of exercise? What is exercise? You know, how can you fit it in their lives, because you can’t go to the gym five times a week if you can’t afford. Issues like that, you know, you've got to consider them. You have to learn the way people see these things. [...] So it’s one thing saying it and one thing is getting people to understand, getting them to see how it can benefit them and often helping them to make their choices.”

HCP#3 - P.2; L.39.

To reiterate, healthcare professionals reported promoting successful T2D management during adaption by:

1) Listening to patients’ concerns;

2) Finding a trigger for action; and

3) tailoring information in light of this, as well as encouraging patients to reflect on fitting clinically-recommended behaviours into their lives.

Thus, healthcare professionals perceived barriers or enablers to the successful management of adaption in the same way as diagnosis, as patient-related i.e. relating to resistance or willingness to learn, absorb and act on information and clinically-recommended behaviours.
4.2. *Patients’ perceptions, understanding and experiences of adapting to living with T2D*

Patient participants were asked to recall and describe how their lives had changed since diagnosis, and what impact T2D had on their lives. Patient participants spoke of periods of time when they assessed the day-to-day ramifications of managing the manifestations of T2D and following clinically recommended behaviours. Whilst exploring these ramifications, patients also described how, these ramifications were accommodated into their day-to-day lives through adjusting their circumstances. In the patient participant sample, four ways in which patients assessed, realised and integrated the ramifications of T2D on their lives by adjusting their circumstances (i.e. adapted to living with T2D) were found:

1) Developing a causation account of T2D;

2) Adjusting use of time to adapt to living with T2D;

3) Adjusting close relationships to adapt to living with T2D;

4) Adjusting relationships with healthcare professionals and use of health services to adapt to living with T2D.

These were co-occurring themes and patient participants adjusted each of these areas simultaneously and in relation to each other.
4.2.1 Theme One: Patient participants’ accounts of developing a causation account of T2D

When questioned on how their lives had changed since diagnosis, and often in discussing how they were diagnosed, all patient participants described what they perceived to have ‘caused’ T2D. This was one theme within the adaption section, and was comprised of four sub-themes.

Some patient participants perceived T2D as:

a) Having originated from within their bodies, e.g. T2D as a hereditary condition, or resulting from the process of ageing;

Other patients saw T2D as:

b) Originating from causes external to their body, e.g. as a result of taking an unrelated medication or migration from another country.

However, conjoined with this, patient participants also reported factors which contributed to, or aggravated the effects of T2D, i.e. its onset and severity. These factors were seen as having contributed to, or aggravated the original ‘cause’ or source of T2D. These contributing factors were seen as both:

c) Individual in nature, e.g. a person’s behaviour; or

d) Socio-contextual in nature e.g. working conditions

These contributory factors were perceived as having triggered the condition.

Sub-theme a: Perceiving T2D causation as within the body

The most common T2D causation source reported by patient participants was the understanding that T2D was an internal disposition. In the majority of cases, an association with T2D running in families was described:
“Of course, you are going to be interested in this, so I might as well tell you that my father was diabetic, so there is the hand-me-down, the way it happens like that.”

PTI# 3 (f) - P.8; L.43.

“It runs in my family actually. Quite a few members of my family – that’s the older ones like my great grandmother, my grandaunt had it and some of her sisters had it.”

PTI#1 (f): P.1; L.29/P.2; L.17.

This association was described in terms of genes, rather than families having environmental commonalities.

Other participants saw T2D as “...a condition of age...”, where T2D had arose with the gradual antiquation of the body - where T2D was seen as a characteristic of general ‘wear and tear’:

“I consider it to be a condition of age, not a disease”

PTQn#5 (m) – P.3

Ageing of the body was perceived by participants as deterioration of the body, rather than a hereditary ‘disposition’.

A further internally-focused causation account was perceived by those who had an existing illness and framed T2D as a ‘knock-on’ corporeal effect of these conditions – thus, the source was again seen as internal to the individual.

“...I am a diabetic because of the drugs given me for HIV, it turned me into a diabetic, that turned me into a person with high blood pressure, that gave me problems with cholesterol and now I have got angina.”

PTI#10 (m): P.1; L.50
Equally, where there was a sudden and/or severe onset, the internal nature of onset was perceived as a sudden failing of the body:

“I am a 66 years, I feel like my energy’s gone. I have been exhausted. I don’t even feel I am living, I am existing through some medicine I am told to get.”

PTI#20 (f) - P.4; Line #52.

In all the instances above, T2D is seen as an internal disposition or process which occurred within the body. Equally, there were examples where the physical manifestations of T2D were not always visible to the patient participants but embodied causes were implied:

“The diabetes was happening in my body but I didn’t know.”

PTI#15(m) - P.1; L.16

Sub-theme b: Perceiving T2D causation as outside the body

Other patient participants saw T2D to be caused by factors external to their body, which caused them to develop T2D. Here, a patient participant described her belief that the effects of migrating from Jamaica to the UK had led to her developing T2D.

“I am one of the West Indians that came over here in the late 50s, a very high percentage of us are diabetics. We all catch it”

PTI#18 (m) P.7; L.9.

Equally, another participant described his belief that taking part in clinical trials for hay fever had resulted in him developing T2D.

“I was suffering from hay fever badly and I went to [Name of] Hospital and I was sent off for a drug trial along with other patients. The tablets they gave me were… I had to take about twelve tablets within an hour or two hours and they were very, very large. And within a few hours of taking them I realised that I was passing a lot of water, I was thirsty and I was drinking quite a lot. And then, I told the doctor that was conducting this experiment with me what happened, then they took me to see another doctor and he [intonates towards the 2nd

160
Doctor] told me that I had diabetes. But it was caused by those tablets I was taking – disrupted my body’s system.”

PTFG#3 Participant NB (m) - P.2; L.10

Here we can see participants perceived an external source to the illness causation which impacted on the body, resulting in T2D.

Sub-theme c: Socio-contextual contributors to T2D causation

Although patient participants reported causation sources - describing factors internal or external to the body as causes of T2D – many participants also described factors which had contributed to T2D onset and severity. The majority of participants perceived these factors as socio-contextual in nature. The participant (below), for example, described how ‘diabetes’ had been in the family (internal to the body), but went on to describe a belief that working conditions aggravated and contributed to developing T2D:

“I had a job working in Saver Centre on the checkouts and I used to sit there for long periods without moving, and in the end - of course - the veins all down the back of the leg. I think they sort of stopped the blood getting through there, on that stool, when I say a long time, I used to sit there illegally for seven, seven and a half hours at a time, without getting up.”

PTI#7 (m) - P.2; L.30.

Another example of a socio-contextual factor perceived to contribute to T2D onset and severity was the participant cited earlier who saw migration as a cause of T2D, i.e. T2D having a source outside the body. The participant went on to specifically describe aggravating factors such as gradual changes in ‘culture’ and ‘diet’ that the socio-contextual upheaval of migration engenders.

“It becomes cultural without you even knowing, because your diet has changed, especially with fast food, your chances of diabetes are increased because of your diet.”
Equally, patient participants saw socio-contextual factors such as access and quality of healthcare provision as contributing to the onset and severity of their illness (socio-contextual factors). One example is the participant above who noted: “... you would have thought the health professionals would have spotted it.” (PTI#10(m):P.1;L.22). Equally, in some cases, patients found healthcare professionals’ emphasis on self-management and empowerment confusing, suggesting they felt more should be done to support people adapting to living with T2D:

“And they just keep saying: I can do this or do that and your blood sugars are all over the place - and asking me what I am going to do about it. And they are supposed to tell me!”

PTFG#2 Participant - ME (f) - P.6; L.21.

Here, a perceived lack of support acts as a barrier to adaption. Related to this, some patient participants felt that if T2D had been identified and managed in a different manner – contributory factors would have had a less impact on their health.

“When you start to, when I started on tablets... and because my blood sugar keep getting higher, I want you know, positive treatment for it, but they increased the tablet, they only increased my tablets from year after year.”

PTI#20 (f) - P.1 ; Lines#:48.

Thus, we can see that contributory factors can also be perceived, by patient participants, as barriers to adapting to living with T2D.
**Sub-theme d: Individual contributors to T2D causation:**

When discussing the causes of T2D, patient participants also saw personal and individual factors, in particular health behaviours, as contributing to the onset and severity of T2D. Only a few participants referred to their own behaviour as (previously) contributing to the onset and severity of T2D – and these participants had all been diagnosed for more than two years suggesting this notion came with time and retrospection.

“I've been a bad patient, had all the chats about amputation, blindness - but it didn’t work. I wasn’t in that place at the time.”

*PTI#14 (f) - P.5; L.25.*

However, these individual contributors to onset and severity were rarely reported as a wilful rejection of ramifications of T2D (n=1), rather participants discussed their past behaviour in the context of having a confused or poor understanding of how to manage T2D. Frequently, these participants had followed the hospitalisation route:

“At first I was a terrible patient. Dr [Name] would sit down with me and show me how to work out my insulin and do my daily testing. That is when I had hypos, especially in the morning, I would do my pen then I started to feel them coming – I was terrified. But I had been trying to take the same amount each time to make sure I knew what to do. So I began to feel unsafe doing it myself, but gradually I have been able to get it under control.”

*PTI#22 (f) - P.1; L.30.*

Presumably, the increased severity of T2D at diagnosis for patients diagnosed as a result of hospitalisation meant that these patients were required to learn to adapt and self-manage at an accelerated rate to allow resumption to their day-to-day lives.

Individual contributors to onset and severity were often indentified as patient level barriers when patients compared themselves with other people living with T2D. Participants frequently stated the belief that for ‘other’ people living with T2D had contributed to the onset and severity of their T2D through their lifestyle and behaviour.
“[O]ther people have slightly different problems. The ones that are overweight and cannot lose it, and you listen to them and watch them eat and think: Mm, that’s why you’ve got diabetes! You end up having a giggle.”

PTI#18: P.5; L.27.

The majority of patient participants drew from factors in their socio-contextual circumstances to explain the severity and onset of T2D. This, combined with the perception of the causal source (as inside or outside the body), provided a personalised explanation of why T2D had occurred in the body. Patients acknowledging T2D causative source created an impetus for patient participants to make adjustments in their lives to accommodate living with T2D, and minimise the effect of contributory factors. As making adjustments to day-to-day life required effort, people perceived as poorly managing T2D were seen as not ‘making an effort’. In summary, individual contributors to T2D onset and severity (i.e. causation) were either related to early uncertainty about managing T2D, or more generally seen in a pejorative fashion by patient participants.

In overview we can see that patient participants held an understanding of how T2D had occurred at the physical level a causal source - with sources of T2D located as internal and external to the body. At the same time, people living with T2D also saw the onset and severity of the illness as aggravated by either individual or socio-contextual contributory factors. In the figure below we can see how these perceived causal sources and contributory factors interplay to create a causative understanding. As some patient participants drew from both individual and socio-contextual contributory factors in their accounts, it was not possible to add patient participant numbers (hence, the figure presents ideal types).
Figure 4: Patient participants’ causal understandings of T2D - How causal sources and contributing factors are combined.
We can see that patient participants fashioned different combinations of causal sources and contributors to T2D to create a causation account. The most commonly reported causation account was an internal causal source with socio-contextual contributory factors (causation account II in the previous figure).

In reporting factors they perceived as contributing to T2D onset and severity, patient participants described poor management of the condition (by self and healthcare professionals) as having contributed to onset and severity, and thus having created barriers to adapting to living with T2D (hence, informing the barriers aspect of research question 2).

A few participants had developed causative understandings which were associated to their route to diagnosis, e.g. some patient participants with co-morbidities saw the source of diabetes as being internal to the body. Those with a hospitalisation diagnosis were also more likely to report initial uncertainty about managing T2D as a barrier to adapting to living with T2D. This suggests T2D-related factors, relating to severity at the time of diagnosis can present barriers to adaption.

A few participants reported contributory factors at the individual level, i.e. patient-related barriers. Only one participant reported wilfully resisting clinically-recommended behaviours. In the main, patients who had experienced individual contributory factors reported that early attempts to adapt to T2D self-management were thwarted by uncertainty about, and poor understanding of, performing the day-to-day tasks involved in managing T2D. This tallies with patient participants accounts in the previous section on diagnosis, which described a period of uncertainty about how to respond to the physical manifestations of T2D following diagnosis. This suggests that uncertainty about how to respond to the physical manifestations of T2D following diagnosis, can linger and present a barrier to integrating T2D-related needs into habits of day-to-day life. At the health service level, a patient’s route to diagnosis can, in some cases, shape the barriers patients experience in adapting to T2D.
The majority of patient participants reported socio-contextual related factors as contributing to the onset and severity of T2D and presenting barriers to adaptation which required adjustment of day-to-day life. Factors such as social upheaval and poor working conditions were innervated in the onset of T2D in some accounts. Equally, poor management at healthcare professional level was seen as contributing to severity of the condition, and posed barriers to adapting to living with T2D. By acknowledging that factors at these various levels had contributed to T2D, patient participants made adjustments to their circumstances so the effects of these factors could be minimised (discussed further below).

Causal understanding tended to reflect the circumstances of people’s lives, and incorporated their social circumstances, family histories, previous health status and significant events in their lives. Hence, what is significant is that all participants held a causal understanding which acted as a spur for the need to adapt to living with T2D. Causal understanding, appeared to only obliquely shape ways or styles of adapting to, and self-managing, T2D. Causal understanding was a signpost that patients had accepted the presence of T2D within the body. This led patients to identify contributory factors which aggravated onset and severity, and explained T2D onset and severity in the context and circumstances of their lives. As such, holding a causal understanding by itself enabled patients in adapting to living with T2D (hence informing research question 2). As will be demonstrated in the sub-sections which follow, patient participants adjusted their circumstances in different ways to accommodate the need to adapt.
4.2.2. **Theme Two: Patient participant’s accounts of adjusting the use of time to adapt to living with T2D**

The second theme found in the patient participants’ accounts of adapting to living with T2D related to how their use of time was adjusted in day-to-day life. Integrating living with T2D into day-to-day life involved patient participants dedicating time to the practical necessity of meeting T2D-related needs. Patient participants reported making adjustments to their use of time throughout their T2D ‘career’, especially as circumstances, severity of the condition and/or treatments changed:

> “Just when I think I have things under control there’s something else, it breaks out again, we’re back to almost square one. Lots more drugs, and... and consultations, I think I may have some neuropathy in my hands, and dealing with that and more pills and doctors ... You can end up spending your days just getting by. They... they say well Mr [Name] these things take a little while, I said yes, you’re always saying a little while.”

*PTI*# 7(m) - P.3 ; L.40.

Hence, adapting the use of time to meet the needs of T2D was seen as a recursive process, recurring intermittently with severity, new symptoms, new medications and so forth. The quote below highlights the single participant who was initially shocked and disavowed T2D diagnosis, that although initially denying the diagnosis, she eventually realised that being mindful of the needs of T2D meant being able to respond to T2D in the future:

> “I just thought, okay, because I kept saying I hadn’t got it, well okay I’ll go. They [doctors] kept telling me that I’ve got it, and I kept denying that I’d got it, and then I suddenly thought I suppose I’d better go and see what they talk about, information and that. So I thought okay I’ll go and get some more information and see what it’s like, and see if I have got it. At first, I felt out of it, because everybody was saying they all need this injection or they take these tablets, but I was just sitting there thinking I haven’t got it, because I’m diet controlled. So I was saying I haven’t got it, but I suppose afterwards, after I listened to it, and I think if you don’t diet control it properly or whatever that’s how it can develop and how it can go.”
Hence, accepting T2D diagnosis led to people acting on this diagnosis. As discussed, most patient participants had developed an awareness of the physical manifestations of T2D during diagnosis, and some had experience of managing symptoms or had seen T2D in their family. All patient participants had developed a causal understanding which prompted adaption to living with T2D, and as shown in the quote above, most patient participants received or sought information about the condition.

Within the theme of ‘adjusting the use time’, three sub-themes were found:

a) Iteration (Adjusting immediate time);

b) Retrospection (Looking back in time to assess the status of T2D and to gauge progression/improvements);

c) Prospection (Looking to the future to assess impact of living with T2D for future plans/goals).

Patients adapted by changing their routines and circumstances in their lives (adjusting their present, immediate use of time). Patients also looked back in time to assess the severity of their illness (retrospection) and looked forward in time and adjusted their future plans in light of T2D (prospection).

Sub-theme a: Iteration (Adjusting immediate time)
Patient participants reported that T2D had impacted on their use of time in an immediate way, as time needed to be dedicated to tend to the needs of T2D.

This process was often viewed as burdensome:

“[I]t has to be planned to the finest detail, just in case I miss a bus or over-exert myself. I am more anxious definitely, it’s hard when you are counting down to your next tablet, next meal... to be, you know... to enjoy myself as much as I used to. At first, I’d find it difficult to remember all the things I had to do, it’s a difficult routine, a care-worn life being a diabetic.”

PTI# 22(m) - P.2 ; L.5.

Establishing how to use time to meet T2D needs was reported as an iterative, day-to-day process. Above we can see that adjusting how time was used was often seen as placing restraints on time and on routine activities. The availability of immediate and ‘spare’ time was diminished as patient participants adjusted their use of time to accommodate the needs of T2D.

Participants also reported that time pressures meant socially-organised activities were restrictive when living with T2D and posed barriers, particularly circumstances where participants felt they had little personal control over time. For example:

“When I first went to the new job they said to me that lunch was an hour – when I knew on my medication I’d need to take two half-hours because I needed to eat with them. If you take an artificial insulin you can’t switch it off - you have to eat. I’d been there two weeks, and you know, you don’t want to look like you’re making excuses and issuing demands, so I just went on like that. But I thought I was going to hypo, it’s gentle at first – but I felt that, felt it coming. I had to explain to them that diabetics need to eat but they wouldn’t let me do that. It got to the point where I was just doing it without their permission – taking two half-hours so I could eat”

PTI#18 (m) - P.2 ; L.41.

Conversely, many patient participants reported a gradual acceptance that time needed to be devoted to T2D, and that restrictions could eventually stabilised into routine behaviour.

“Most of the inconveniences become less obvious to you, you stop noticing them. They become part of your life, like catching the train in the morning, or brushing your teeth. It becomes part of your life. My colleagues must notice it –
my strange routines and foibles, but I have to be quite meticulous in planning things, so they must find it strange. Even if I do cheat, a glass of wine or little piece of something sweet. Then, I have to make sure I have to get home in time [to take medication ...] I have a plan and a routine. It must, I feel, it takes a bit of your personality, if you can imagine, it’s there in the background – it’s always there. But you get used to it’’

PTI#14 (f) - P.3; L.44.

Participants living with severe complications, often viewed adapting to day-to-day activities, more neutrally, as therapeutic. These patient participants often planned timings in detail as time was required to overcome physical restrictions they experienced and routine tasks, although burdensome, were seen as achievements. Below, a participant discusses his experiences of adapting to day-to-day living after having his leg amputated for T2D-related complications.

“I mean I realise, you know, I'm not going to get any better, I just have to take it easy and not do silly things, I try and get as much exercise as I can, and I have to sit with my foot up, above my heart line so the blood flows back easily to the heart. So I sit there and I do the same thing, I get my wife's breakfast if I can, in the morning. I prepare my lunch, prepare the evening meal, have the evening meal and that's it. I do all the shopping but I can't, I can't, really get out. I can walk with sticks but, I mean I have a friend, we go to exhibitions and things like that - but I get terribly tired after half an hour and I'm looking for a seat to sit down. So just short bursts of what I can do, get myself up, active”

PTI#7 (m) - P.2; L.22.

Other patient participants reported the increased severity of T2D and onset of complications as increasing the time that they needed to be devoted to adapting to living with T2D, but often not being able to devote the time needed.

“When I first have diabetes I was on the tablets, I was on half, then they change it, and still my blood sugars are up and down. I spend my time taking pills and more pills. Then I got a sore and it got better just a little pain here [points to lower leg], it didn’t really cause any problems, but it get worse. They start me on antibiotics, I have one course and go back to the doctor, and he start me on another, but it didn’t work. Then my balance start to go and I’ve got a stick - My life just went down the drain[…] I can’t get to the shop and I rely on my daughter to come and get me. I have a carer who comes twice a week, but she no good. Just moving things and I can’t find them.”
Conversely, it was found that those who had lived with T2D for 2 years or longer and had higher incomes and professional backgrounds reported having adapted to living with T2D by reframing the time dedicated to T2D in positive ways.

For example, one participant described how managing T2D turned from an onerous task of managing of time, to something she now considered to be ‘time to look after herself’:

“...I had little gods I had to make offerings to everyday, sacrifices really. But a friend said to me: it must nice to have that time where I take care of myself. And I thought, yes, she’s right. So, now, I like to look at it like that, as time for myself, looking after myself really.”

Patient participants with higher incomes and professional backgrounds described the process of adaption as using their time more productively.

“Well, a positive thing is that my diet has increased, I mean it’s better because I eat different because I am a diabetic. More vegetables and less starch and that sort of thing, and I wouldn’t have my exercise if I wasn’t diabetic. Since being told, I have been doing exercise twice a day, you know.”

This suggests that aspects of some patient participants’ socio-demographic background – such as greater income and a professional status – combined with experience of living with T2D - facilitate more positive experiences of adapting to living with T2D as their circumstances afford them more resources and greater flexibility. Equally, adjusting use of time was reported more neutrally as a therapeutic process or gradual routinisation, or as largely restrictive by those living with more severe T2D.
In terms of the research questions this sub-theme informs research question 2 relating to barriers and enablers to adaption. Severity of illness was reported as adding to immediate burdens on time which acted as a barrier to adaption (research question 2). Restrictions were also evident in circumstances where personal control time was limited, e.g. working environments – hence, capacity to adapt was restricted and barriers were evident.

With regard to factors enabling control over use of time, the combination of higher income and distance from diagnosis conferred advantages (in terms of socio-contextual circumstances) which facilitated and enabled better control over circumstances and the ability to overcome the immediate day-to-day restrictions on time which complicated adaption to living with T2D. This lead adaption to living with T2D becoming reframed in positive ways. Equally, some patient participants were able to reframe the barriers that increased severity of T2D engendered, by seeing it as a therapeutic part of integrating into day-to-day life after they had experienced complications.

Some patient participants reported successful management as overcoming the constraints on time by establishing manageable routines (informing research question 1 (on un/successful management).

Sub-theme b: Retrospection (Looking back in time to assess the status of T2D and to gauge progression/improvement)

At the same time patient participants adjusted immediate time, they also looked back in time to gauge progression of T2D and how successful their attempts to adapt to living with T2D had been.

First, patient participants looked back in time to see the impact T2D has had on their lifestyle since their diagnosis. The patient participants below are two men with comparable
backgrounds and T2D status, who in comparing the current situation with the past come to different conclusions:

“I'm married, part of it is loss of potency, it ... it hasn't made me a comfortable bedfellow shall we say, and I get various other side effects which include feeling very tired. Normally I would do all sorts of, quite often, ‘do it yourself’ - and my interests were in woodwork and the garden and so on, and I just haven't been able to cope with that sort of thing, which makes me depressed and I'm sure makes my wife depressed. [...] Motivation is part of it but it's also a physical burden, which it never used to be, I used to climb over the roof, up trees, saw off branches, do my woodwork, including wood turning, you know. Without any limitations at all, or problems. Nowadays I hesitate before I do any of that, and climbing a ladder's virtually impossible.”

PTI#2 (m): P.1; L.38/P.2; L.14.

“I can’t do as much physically as I did before, I used to go dancing a lot and I can’t manage to do that anymore. I used to sing but I don’t do that anymore, so really it has affected me in certain ways but a lot of people are far worse off than me. I know I have diabetes so I can do something to make it better.”

PTI#15 (m) - P.1; L.39.

In both cases we can see that comparison of their current life with the past often shapes how patient participants experience restrictions on day-to-day life in the present. In the examples above, the first participant relates his frustration at the restrictions he experienced (tiredness and erectile dysfunction) and saw T2D as a process of gradual deterioration. Whereas the latter participant generally accepted the limitations he experienced as having occurred with time, and make downward comparisons with others. Hence, where a ‘pay off’ for self-managing was found by patient participants e.g. now being able to ‘do something’ about T2D and not being as bad as other people, a more positive continuity is fostered.

“That’s why I do more exercise, because I don’t want to have a heart attack and end up like my Mum did, because my Mum ended up in a nursing home, and she was in and out of hospital because they weren’t looking after her properly, and I don’t want to be like that. She had a cerebral haemorrhage too and after that she never ever walked again. I don’t want my family to have to go through all that.”

PTI# 11 (f) - P.6; L.1./ P.5; L.11.
However, where severity had increased and/or restrictions in lifestyle and/or few health gains have been attained a sense of deterioration and disruption sets in and more time must be given to accommodate the impact of T2D.

“Then my balance start to go and I’ve got a stick - My life just went down the drain.”

PTI#20 (f) - P.4; L.48.

This process suggests that attitudes and expectations of adapting to T2D were shaped by the way patient participants used retrospective timeframes to evaluate the impact of T2D on the day-to-day lives. This process created ‘pay offs’, where restrictions were contextualised or overcome in the present, which facilitated a sense that T2D could be successfully managed (informing research question 1 – gauges of un/successful management). However, diminished expectations and a sense of deterioration were evident when patient participants felt restrictions and felt that their expectations of improvement were not met – creating the notion that the condition was becoming unmanageable.
Sub-theme c: Prospection (Looking to the future to assess impact of living with T2D for future plans/goals)

In the examples above, living with T2D affected people’s use of routine and immediate time, and retrospection was used to gauge the impact of T2D on their day-to-day lives. In these themes we can see that adaption to living with T2D impresses on peoples’ futures in two ways:

1) Living with T2D made patient participants aware of the need to plan so that routines and day-to-day circumstances can be adjusted to incorporate time for managing T2D;

and

2) Living with T2D made patient participants aware that current effort could shape future health outcomes.

Hence, living with T2D was often reported as a turning point. The participant below, for example, had brought forward plans to retire near the sea in light of living with T2D.

“The other thing about what we have learned, is that where we are moving to, Lancing is very flat, I didn’t realise how flat it is. I know there are the South Downs but the actual ...where we’ll live in the town is very flat, and it will be good for walking for me [to get exercise]. People just sit back and give up. What we have is a great sense of humour when it comes down to it, we can tell a funny story. The best thing you can do is turn the television off and get out the house. When you get to our age you have to have the philosophy that time is running out.”

PTI#18 (m) - P.12; L.3.

Another participant seized on living with T2D as an opportunity to travel:

“That's when I retired, I had the opportunity to retire early, and I thought it was the best option. The stress, the workload - it's one of the worst things you can do - is find yourself under that sort of pressure. I had a pension and savings, and I realized it was a good time.... I go travelling a lot now, I've been to India, South Africa, the States... That's the strange thing really, my quality of life has actually improved.”

PTI#13 (m) - P.2; L.13.
Equally, future plans were often reported as disrupted by T2D onset, particularly where T2D was severe. The participant below discussed how she had worked whilst raising her children as a lone parent – and how her plans for retirement were disrupted:

“I had planned to retire when they [the children] had gone, I had pick them up and drop them off to school every day and I work all night, and I know this only when they old enough to stand by themself. [...] (Now) I am existing through some medicine I am told to get. I mean, why has this happened? This is the time for me, and this happen.”

PTI#20 (f) - P.2; L.6 / P.4; L.48.

Overall, participants adjusted their future use of time to accommodate living with T2D, and often adjusted future plans in light of living with T2D. Some patient participants whose condition was severe saw the impact of T2D as disrupting their future plans. In this sense, increased severity of the condition appeared to act as a barrier to patient participants adjusting personal circumstances in order to accommodate the ramifications of living with T2D. However, other patient participants were in circumstances that afforded them the opportunity to bring forward their future plans, or ‘seize the day’ in a manner that accommodated T2D. This process of adjusting the use of time to adapt to living with T2D was found to be recursive and happened throughout patient participants’ experiences of living with T2D. The process was used to evaluate: 1) the ramifications of T2D for current circumstances; 2) the impact of T2D, as well as 3) future circumstances and expectations in light of the ramifications of living with T2D (see figure 9 below).
Figure 5: The 3-part iterative process of adjusting time in order to adapt to living with T2D.

The process was reported as engendering various barriers and enablers to adapting to living with T2D, as well as examples of what constituted un/successful management.

The majority of factors which acted as barriers to adjusting time were related to the onset of complications and/or the severity of T2D, i.e. T2D-related. Increased severity of T2D added to immediate burdens on time patient participants experienced, thus acting as a barrier to adaption (research question 2).

A further socio-contextual barrier was identified in managing immediate time, i.e. where personal control of time was limited (e.g. working environments), the capacity to act in an adaptive fashion was restricted and barriers were evident.

Conversely, the combination higher income and distance from diagnosis was associated with conferring advantages (at the level of socio-contextual factors). Access to these socio-contextual resources facilitated and enabled control over personal circumstances and the ability to overcome the immediate day-to-day restrictions on time that living with T2D engendered, as well as adaption to living with T2D being reframed in positive ways.
Also, at the level of T2D-related factors some patient participants were able to reframe the barriers that increased severity of T2D created, by seeing it as a therapeutic part of integrating into day-to-day life after they had experienced complications. From the data it was unclear why or how this occurred. One explanation could be that severity increased encounters with healthcare professionals and the notion of adaption as a process of attaining self-management is cross-pollinated.

Patient participants reported predominantly patient-related factors as contributing to successful adaption through use of time. Overcoming the day to day restrictions of T2D on immediate time through time-management, and the establishment of routines, was seen by patient participants as successfully managing T2D (research question 1). Examples were also found in patients’ accounts of retrospection. The manner in which patient participants used retrospective timeframes to evaluate the impact of T2D on the day-to-day lives created ‘pay offs’ (where restrictions were overcome, routinised or contextualised) which demonstrate T2D could be successfully managed. The inverse was also apparent, i.e. a lack of improvement as denoting T2D as unmanageable (or unsuccessfully managed).

4.2.3. Theme three: Patient participant’s accounts of adjusting close relationships to adapt to living with T2D

The patient participants interviewed – like all people - lived in a network of social relationships. As T2D-related needs arose, these needs most commonly impacted within close, personal relationships. Outside a few mentions of the work environment, it was the way T2D was managed within the domestic setting that was most frequently discussed.

In analysing the data, two main sub-themes were identified in relation to adapting to living with T2D by adjusting social relationships:
a) Visibility within the household; and

b) Assigning roles and responsibilities

Sub-theme a: Visibility within the household

Only one (newly diagnosed) participant reported not having disclosed to her friends and family that she was living with T2D. Although she felt that she may disclose this status in the future, this participant argued that the worry it would caused other others outweighed how serious the condition actually was:

“I think because we’re not actually living near, and I just thought, I won’t worry them.”

PTI#9 (f) - P.2 ; L.36.

Thus, this participant filtered the seriousness of T2D according to whether they warranted disclosure to her family.

Similarly, other participants reported this process of minimising the visibility of living with T2D to allay others’ concerns; this often meant that family members didn’t understand the ramifications of T2D as the person managed alone, accommodating others. For example, participants reported not talking of the effects of T2D, cooking separate meals or managing their medicines privately so that life (for others at least) can carry on as ‘normal’ and existing routines could be preserved.

“He don’t like it because I eat a lot of salads and that, and my husband doesn’t like salads. So I just do his and then I do mine.”

PTI#10 (m) - P.7; L.23.

“They think I’m miserable. I mean, I shouldn’t have no salt, and they put it in. They come, and they use the kitchen, and don’t do what they’re supposed to do. And they taste my food and put salt in it. And I get tired a lot of times. I have my granddaughter all week. My daughter will drop her off at eight o’clock and she
collects her at one. It’s really my husband - because there isn’t anything wrong with him, he should do more! But I find it hard sometimes if I have to look after her and I am tired.”


Frequently, this ‘backstage management’ of T2D was conducted in order to minimise the disruption or worry that family members may experience. This was particularly common in older women. One patient participant reported how T2D was considered by her family to be something personal to her, and she felt that her family did not wish to be bothered by her condition.

“Ostrich behaviour is more comfortable.”

PQn#P.2; L.6.

Conversely, many of those who lived alone often saw managing T2D as something they just ‘got on with’, and reported irritation with family members having concerns about their welfare.

“I watch my diet and that’s really the basic thing that has made a difference to me. I used to love chocolate and sweets and I don’t have them now or very rarely anyway. My daughter was a bit worried at first but I think she has got used to the idea. She works for the health service and so she is very health orientated and she kept ringing me up and asking me how I was and what was I taking and all this kind of thing, but she seems to have settled down a little bit now. Let’s face it, there’s not much you can do about it anyway, you've got to accept it haven't you. I just don’t let it get to me.”

PTI#4 (f) - P.1; L.22.

Many participants reported that domestic routines were altered or adjusted to accommodate T2D often with ‘knock on’ health benefits for spouses and the rest of the household.

“1st Participant: “When I was diagnosed my doctor made an appointment for me to go and see him with my husband, and he sat down for about twenty minutes and explained everything to us. Things like, even. Things like, even a tin of baked beans has sugar in it so you need to consider that. It is very good, and goes into the details of what has caused it, and what the symptoms are and what
you can do to stop your sugar going up. He did spend the time with us, and I think that helped my husband as well ...”

2nd Participant: So he can help you. [...] I feel that the diet is a healthy diet for anyone basically and it must be doing us good – I haven’t put on too much weight and I think that is partially to do with the diet. And again a treat every now and again. My husband eats better too. We are aware of what we eat, we check the labels.”

PTFG#3, Participants TH & DC (f & f) - P.10 ; L.9.

As we can see, within close relationships T2D was adapted to in different ways which entailed differences in the visibility of T2D-related behaviours and preserving existing, or developing new, domestic routines. Where T2D was managed as a visible issue within the household patient participants could get support which enabled meeting self-care needs and often had positive ‘knock-on’ effects for other members of the household, e.g. better diet. However, individual ‘backstage’ management acted as a barrier, as patient participants had to find ways to avoid disrupting daily routines, and meet their needs within existing ‘state-of-play’ and competing demands of the household.

Sub-theme b: Assigning roles and responsibilities

Adapting to living with T2D through adjusting close relationships involved adjusting roles and responsibilities to meet the recommended behaviours of T2D. Where this was done in a visible, co-caring style, tasks were frequently divided up and absorbed within the routine, day-to-day necessities of domestic life.

The clearest example of this was demonstrated by the majority of married, older men in the study, who saw T2D as having very few ramifications for them personally:

“Interviewer: So has your life changed much since you were diagnosed?

Participant: Not really, just what I eat, and my wife does the cooking.”
The above quote illustrates that for some male patient participants a large part of the burden of care is absorbed within the existing division of labour within the household.

Conversely, patient participants with higher incomes, professional and degree-level who had been diagnosed for a number of years (n=4) saw managing T2D as an individual responsibility that came with time, practice and with necessity.

“I have excellent control. All illness creates problems of one sort or another so if you want to cut down on the number of problems - you need to keep your knowledge up to date. If your knowledge is stuck at some point in the past you can’t assume that your doctor is up to speed, you just can’t.”

PTI#10 (m) - P.7; L.18.

“You’ve been given the information, if you care not to, you’re a bit ridiculous.”

PTI#2 (m): P.8; L.1.

These wealthier, more experienced and educated participants’ descriptions of managing T2D frequently described being able to manage their time and their circumstances in a way that allowed them greater control.

On the other hand, many married/co-habiting participants often reported co-caring T2D by dividing up cooking and medication management, and supporting one another.

“She [wife] say the tablets make me better to live with, I’m not under her feet [laughs]. But I don’t feel no different. She put them in the box. Monday. Tuesday. Wednesday. She put them there for me, so I take it. They don’t make me feel no different, but she say I am better.”

PTI#5 (m): P.1; L.30.

However, this co-caring sometimes led to situations of uncertainty where symptom uncertainty and response uncertainty were exacerbated by disagreements between the person living with T2D and their spouse or carer about signs and symptom, and the best course of action to take in managing T2D (co-caring uncertainty).
“Participant 2: He used to suddenly get this bad temper and this bad mood for nothing at all, it just used to come from nowhere, no particular reason ... When he got bad tempered like that... It’s like he's not right. It is irrational, that mood.

Participant 1: Can’t I have a bad mood?

Participant 2: No, this was a dark mood. He’d start to complain, and was very restless, stamping about shouting. I’d go and do the ironing or something, get out from under his feet. It would pass, you know.

Participant 1: If you weren’t fretting over me. I would have checked my blood I know...

Participant 2: You said yourself those things don’t measure properly. In fact, I said those things were rubbish years ago you didn’t listen, and even the doctors say they are now.”

PTI#18 (m = R1 + wife = R2): P.3; L.43.

As we can see this creates uncertainty and disagreement and acts as a barrier to seeking help and support from the close relationship and health professionals.

In summary, the impact that living with T2D had ramifications to patient participants’ close relationships, how this was managed within household involved different levels of visibility and divisions of responsibility. These divisions of labour ranged from those who were highly self-directed to those who share the burden of care, and even a few participants who passed T2D-related care onto others. However, adapting to living with T2D was performed both overtly and covertly – with some participants minimising the visibility of self-caring. This engendered differing barriers and enablers.

One barrier to adapting to living with T2D occurred where patient participants ‘backstage’ managed T2D needs. This meant that no time was dedicated specifically to their needs within the household and become subject to competing demands. We also saw that another barrier to adaption was co-caring uncertainty when co-carers of T2D disagreed on courses of action. As such these barriers (and enablers below) relate to the flexibility of patient participants’ social-contextual circumstances.
On the other hand, the majority of patient participants openly planned and arranged their routines around the demands of T2D. This enabled them to draw on support and ‘ring fence’ aspects of day-to-day routines for T2D-related activities. This also had knock-on effects for the rest of the household, e.g. dietary improvements. Co-caring arrangements were also seen to minimise the ‘disruption’ that living with T2D posed. Hence, flexibility in socio-contextual circumstances, i.e. support within the household and having flexibility within personal circumstances were seen as enabling adaption to living with T2D.

Within this sub-theme, disparities began to emerge between patient participants’ perceptions and understanding of successful management. Differences in styles of adaption which emerged between participants become more pronounced in relation to actual T2D management (and are discussed in the chapter that follows). We can see that a handful of patient participants (wealthier, educated veterans of T2D) had an orientation towards autonomy and personal control as constituting successful management of T2D. These participants were able to influence their circumstances in a manner that enabled personal control of T2D management. This is in contrast to co-caring adaptive styles which sought to absorb T2D management within the durée of day-to-day routine, and ‘backstage’ styles of T2D adaption to minimise disruption to the household. Both of these latter styles sought to neutralise the impact of living with T2D and fit T2D management around their existing circumstances. Hence, again these gauges of un/successful management relate, in degrees, to the flexibility within patient participants’ existing social-contextual circumstances.
4.2.4. Theme four: Patient participant’s accounts of adjusting relationships with healthcare professionals and use of health services to adapt to living with T2D

Patient participants’ accounts’ of adapting to living with T2D provided examples of how they adjusted their relationship with healthcare professionals and use of health services. Two sub-themes were found.

a) Using healthcare professionals and health services as a gauge

b) Using healthcare professionals and health services as a resource

Subtheme a: Using healthcare professionals and health services as a gauge

It was noted in the process of diagnosis, that patient participants who received a diagnosis through screening described how their test results showed changes in their body, i.e. actualised T2D as present within their body.

In a similar way, patient participants read into how healthcare professionals managed T2D, as well as the type of services they had received to judge the seriousness of the condition.

“So I mean I don’t need to see [Name of Consultant Diabetologist] anymore because I either found I can do stuff for myself or I’m getting it from my GP.”

PTI#2 (m): P.8; L.13.

“I’m diet controlled, and my doctor says it is working for me at the moment. So fingers crossed in doesn’t get too serious.”

PTI#9 (f) - P.5; L.22.

The majority of patient participants, however, described using check-ups and appointments as a gauge for the success of their efforts to adapt to living with T2D. In these encounters patients sought to maintain a sense of stability, and check that the
actions they had taken to address the ramifications of living with T2D had worked and/or to get advice and recommendations on their concerns.

“I have a really good diabetic nurse at the doctor’s surgery and she puts me on the right road most of the time. And she seems to be quite happy with the way I am progressing [...] I just do what I have to, and tune the rest out, otherwise I worry.”

*PTFG#3 Participant DC (f) - P.6; L.44.*

Although patient participants often described these encounters as uneventful and routine, the mundane nature of these encounters verified and reinforced the measures the patient participants had taken to address living with T2D, i.e. no news was good news. Advice and recommendations were welcomed from healthcare professionals, and equally, patient participants used contact with healthcare professionals to gauge their adaptive effort.

Conversely, a few older patients (70+) on limited incomes and often living with severe T2D, saw themselves as burdened with care as they felt that healthcare professionals expected them to manage the condition with little or no professional help. Hence, these patient participants felt that the burden of care was tilted too far on them, and gauged this perceived lack of support as a barrier to adaption.

“And they just keep saying: I can do this or do that and your blood sugars are all over the place - and asking me what I am going to do about it. And they are supposed to tell me!”

*PTFG#2 Participants - ME (f) - P.6; L.21.*

Similarly, others reported fractured healthcare services with little continuity, and poor quality care, as a barrier to adaption.

“You have got to build up trust with people and I just feel that my care chops and changes”

*PTI#16 (f) - P.2; L.17*
“I just, I just feel that, you know, when I go to the hospital or to my doctor I just feel that I should be seen by somebody, I mean I should, I know it's maybe asking for too much but I should not be seen by a different doctor every time because it doesn't give a full understanding of my condition. They start you back from the beginning and it annoys me, because it's like my condition is on a computer, you know, they look on a computer, they don't look at me. I might be dying, they're looking at a computer, they're not looking at me! You know, they judge me from the computer, my condition changes, diabetes patients, their condition change, over years, the way I would manage it first, the first day I had diabetes - it's different to now. But they're not looking into it, they're just looking at their computer.”

PTI#20 (f) - P.4; L.32.

This was particularly common in those who felt they were burdened with care and felt they should receive more healthcare professional support. This suggests that 1) where a high level of healthcare professional and service support is expected at the patient level, but not provided to expectation, barriers are perceived, and that 2) poor continuity of care at the health service level is also perceived as a barrier to adaption.

Subtheme b: Using healthcare professionals and health services as a resource

We have seen that patient participants gauged the seriousness of their condition, and the success of efforts through their encounters with healthcare professionals and service use. At the same time, many patient participants saw healthcare professionals and health services as a resource, and drew from this resource in different ways to adapt to living with T2D.

The majority of patient participants described self-regulating their use of health services saying that they felt their condition wasn’t too serious and they did not wish to waste NHS time and resources.

“It is so difficult to get an appointment when you need one. I don’t like to bother the doctor too much, they are so busy when I go for my check up with the nurse. And, you know, there’s not enough to go round in the NHS, it’s always full of people when
I go there, or to the Diabetes clinic, and you see people in a far worse state than you so you think you are just wasting their time really, when there isn’t anything wrong with you.”

PTFG#3(f) Participant (TH) - P.5; L.21.

Equally, participants perceived people living with T2D who were not managing well as wasting resources:

“I talk to this fella’ at the clinic, he isn’t a good diabetic, he’s a bad diabetic. He drinks like a bleeding fish and goes out without meals, he’s a bugger. I know he’s got problems, he’s an old boy, but he’s being silly isn’t he? I mean, we’ve had conversations about not missing meals and giving yourself extra insulin to juggle things, but he don’t listen. [...]I know he’s a fool to himself but there’s people in a worse state than him, but he don’t think of that, that he’s just wasting everybody’s time.”

PTI#18 (m): P.6; L.7.

Overuse of scarce health resources was seen by some as irresponsible, indicating failure to adapt successfully to living with T2D, and often as a moral failure. As such, the understanding of increased severity with increased service use (and poor self-management) may act as a barrier to self-referral. Hence, successful management was equated with appropriate (usually minimal) use of health resources.

As also evidenced in previous themes, a few participants who had been diagnosed 2 years or more, and who had higher incomes, sought to enhance their personal control of T2D by securing resources from healthcare professionals and healthcare services. Although wishing to maintain minimal contact with health professionals, this group focussed on the quality of these encounters and maximising the benefit they could get from using health services to assist them in autonomously self-managing. The patient participant below described the need to be assertive to secure health resources:

“Patients don’t always get what they are entitled to - but they often get what they deserve because they don’t question anything. So I have got to be really assertive.”

PTI#10 (m): P.5; L.12.
This ability to define, and subsequently address, their needs through health service provision, was seen by these patient participants as enhancing the patient participants’ capacity to adapt. Interestingly, (as is discussed in the next section) this group sought to minimise the need to use health services, other than to gain access to treatments that would enhance their autonomy.

Those who felt that they carried a burden of care also saw themselves as being denied resources they needed. The patient participant below describes

“It was the medication I was on [...] I wait[ed] weeks for an appointment, and when I get one ... I sit and wait, they always make you wait. And when I see the her [doctor] they just say ‘let’s give it more time and see’, so I say but I am feeling dizzy, sick ..you know ... But she just say I am very busy I will make you another appointment, like I take up too much of time ... and I am feeling sick!”

PTI#20 (f) - P.4; L.48.

This sub-theme shows that when healthcare professionals and health services are perceived as a resource, use and frequency of contact with health resources is seen to enable, or provide barriers to adapting to living with T2D. Some viewed lack of contact as a denial of resource provision, and hence a barrier to successful adaption. Equally, some argued that minimal contact with services should be used productively to enable better adaption in an autonomous fashion. Others saw the degree to which they had secured continuity of care as a gauge of un/successful management.

In overview we can see that, adapting to living with T2D, patient participants used healthcare encounters in different ways. Therefore, the barriers and enablers to adapting living with T2D reported are largely healthcare professional and health service (system) related. Those with severer progression in their T2D, who felt burdened with care, reported a perceived lack of support from health services as a barrier to adapting to T2D. This suggests a tension between patients living with severe T2D-related factors, and factors at the healthcare professional and
service level. Patient participants also reported being unable to benefit from health services due to a lack of continuity in care, this acted as a barrier to adapting to living with T2D. Another potential barrier to early self-referral during adaption identified was the association patient participants between increased severity, increased service use and poor-self-management.

Patients used health services and professionals to different effects. Most participants saw appropriate access to health service resources as enabling better adaption to living with T2D. It was found that the pattern of socio-contextual enablers (education and income) was again evident, i.e. with those seeking to autonomously manage T2D reporting the need to be assertive with healthcare professionals to secure resources.

Patient participants gauged the seriousness of their condition by how they were referred within services and encounters with healthcare professionals. As such, successful management when adapting to living with T2D was equated with appropriate and judicious use of health services and healthcare professionals. The inverse was also reported, i.e. those poorly managing were seen as wasting health resources. However, we have seen that those with severe T2D saw poor quality services and lack of continuity of care as a barrier to successful management.

4.2.5. Overview of themes relating to patients’ experiences, understanding and perceptions of adapting to living with T2D

Patient participants described a process of developing a causation accounts which explained the onset of T2D in the context of their lives, and realising the ramifications of living with T2D through the impact that T2D had on the day-to-day aspects of their lives. Figure 10 shows the different elements that make up to the adaption process:
Figure 6: Themes in patient participants’ perceptions, understanding and experiences which comprise the adaption process.

- Prospection: Realising ramifications of T2D by adjusting future plans and expectations (e.g. working towards a future health outcome or change to current lifestyle)
- Retrospection: Realising ramifications of T2D by comparison with the past and whether there are ‘pay offs’ (e.g. evaluating progression of condition)
- Iteration / Integration into day-to-day life: Retrospective, prospective and immediate ramifications are realised and time & resources are devoted to meeting these needs or goals

- Use encounters with health services and health professionals as a way to gauge ‘seriousness of condition’
- Use encounters with health services and health professionals as a way to secure resources

- Internal hereditary disposition with onset and severity aggravated by aspects of individual’s behaviour
- Internal hereditary disposition with onset and severity aggravated by environment/socio-contextual factors
- External environmental causation with onset and severity aggravated by individual’s behaviour
- External environmental causation with onset and severity aggravated by socio-contextual factors

- Patient participants realised the ramifications of T2D through impact on daily routines
- Theses ramifications were managed 1) alone in a ‘backstage’ manner to minimise visibility and disruption or 2) managed individually or 3) co-managed visibly in daily routines.
- Patient participants assigned roles and responsibilities towards self (to minimise visibility or allow more autonomy) OR towards others (T2D co-managed in day-to-day routines).

- Adjusting close relationships to incorporate T2D management
- Developing a causation account of T2D
- Adjusting use of healthcare professionals and health services to manage T2D
- Adjusting use of time to incorporate T2D

- Use encounters with health services and health professionals as a way to gauge ‘seriousness of condition’
- Use encounters with health services and health professionals as a way to secure resources
As is expected, patient participants had different life experiences and circumstances, hence realised the ramifications of T2D in different ways and to different effects. These different strands of adaption were adjusted singularly or in unison, and balances were struck between different elements, as can be seen in the extended quote below:

“Well, socialising, parties, birthdays... Work things, lots of things at work happen in the lunch sessions in the pub [close relationships] I go occasionally... Less than before. Yeah, I do have the occasional drink, a beer or whatever, you can’t become a hermit with it, it’ll be too hard to keep a straight course. You make sure you’ve taken your tablets first, and don’t drink till you’ve filled up [time]... so.. So there are cheats, at the meeting I went to they said to us that you can more or less have anything you like as long as you don’t go too mad with it. But people tell you: ‘you can’t have this or that, sweets are dangerous’... you know – the doom-mongering, it’s not like that at all. The practice Nurse she is err... Yes, she’s very good, she helps us [healthcare professionals] – I remember when I was first diagnosed and she told me I’d need to change my diet’ I said, I don’t cook, my wife cooks’ [close relationships] and she says: ‘well, bring her along next time’ and we did. She took us through it all - brown not white bread, rice, salads... you know. She give her all these pamphlets, and recipes for her to take. So I can take a lunch box to work now, she knows what I am eating [laughs]. I think she worried less after that, could she could understand what it was all about, you know, nothing we can’t handle.”

Patient participant #21: Page 2: Line #12. [area of adaption added in parenthesis]

Adaption was also reported as a recursive process which happened throughout the course of living with T2D. Establishing a stable routine by adjusting these different elements of adaption was seen as managing adaption successfully. Hence, adaption occurred through patients mediating between their T2D-related concerns and the ramifications of living with T2D for their social contexts. As we will see in the next section, how these different elements of adaption were fashioned into a routine contributed to styles of self-management.
Summary of patient experiences, understanding and perceptions of barriers and enablers to adaption to living with T2D:

Barriers:

One T2D-related factor that posed a barrier to adaption for patient participants was increased severity of the condition. It was found that the increased severity engendered in a hospitalisation route to diagnosis created uncertainty about how to manage the illness once stabilised, as T2D was seen as a sudden attack within the body. Equally, experience of increased severity led patient participants to feel that T2D was burdensome as large amounts of time were dedicated to tend to the needs of T2D, and mundane, routine activities were equally time consuming due to the effects of complications, e.g. the mobility issues discussed in relation to amputation above. These participants were also more likely to describe their future plans as having been ‘disrupted’ by living with T2D. Where increased severity was present, patient participants frequently perceived a lack of support from healthcare professionals and health services.

In terms of patient-related barriers, reports of wilfully denying T2D and resistance to adaption were rare. Rather in developing a causative understanding of T2D, some patient participants believed that some (other) people living with T2D had contributed to the severity of their condition due to their behaviour, e.g. overeating. However, many also reported that the initial uncertainty they experienced in performing T2D-related tasks following diagnosis had contributed to the severity of the condition.

Poor management of T2D at healthcare professional level around the time of diagnosis was also seen as aggravating T2D severity. A perceived lack of healthcare professional support was also seen, by patient participants living increased severity, as contributing to the burden of adapting to living with T2D. Health service (systemic factor) barriers were closely
associated with the health professionals which patient participants used as both as a gauge of their adaption efforts and as a resource for self-management. Patient participants also reported being unable to benefit from health services due to a lack of continuity in care, this acted as a barrier to efforts to adapt to living with T2D. A further potential barrier to early self-referral during adaption related to some patient participants perceiving increased service use to be associated with poor self-management, and that the condition was not ‘serious’ enough to warrant health service utilisation.

The majority of patient participants reported socio-contextual factors as either aggravating T2D (e.g. working conditions) or as a cause of T2D (e.g. migration), and that addressing these factors were the main barriers that presented barriers to adapting to day-to-day life. This became more apparent when patient participants discussed adjusting their use of time to adapt to living with T2D. Where personal control of time was limited by socially-regulated practices, e.g. in a working environment, restrictions on the ability to adjust time to meet T2D-related needs was restricted and posed an adaptive barrier. Equally, the flexibility of, and social support available in, patient participants’ day-to-day lives, contributed to the barriers they experienced in adjusting their close relationships.. Those managing T2D alone in a ‘backstage’ fashion frequently encountered competing demands to meeting their T2D self-care needs. Those who had established co-caring arrangements were better able to adapt household routines to adapt to living with T2D, but co-caring was subject to periods of co-caring uncertainty (disagreements about managing T2D).

Enablers:

Gaining a causal understanding was found to provide explanations for the onset of T2D in the context of patient participants’ lives, and, as such, enabled patients to begin the process of adapting to T2D (by making adjustments within their lives). T2D-related factors played a part in patient participants’ perceptions of adaption, as, uniquely, some patient participants with
severe T2D described reframing the increased time spent on day-to-day as therapeutic, rather than seeing this as a barrier to adaption. It was speculated that this may be due to increased contact with the healthcare professional level. Although patient participants used healthcare professionals and health services in different ways, many reported that contact allowed them to access health resources and gauge the success of their efforts which facilitated adapting to living with T2D. Some participants who had been diagnosed with T2D for 2 years or more reported the ability to manage time to meet the needs of living with T2D, suggesting that the process of adaption occurred over time.

However, factors identified as enabling adaption to living with T2D were largely related to patient participants’ socio-contextual circumstances. In terms of managing time to meet T2D needs, patient participants with higher income and educational attainment tended to orientate towards managing T2D autonomously. These participants reported enablers relating to managing time to adapt to living with T2D. These included the ability to adjust future plans in light of T2D, purposively manage time to tend to T2D, and positively reframe the time dedicated to T2D related needs. Some patient participants reported that support within close relationships and co-caring, particularly within the household, appeared to minimise disruption and lead to the establishment of routines to meet T2D-related needs. Co-caring arrangements frequently had positive knock-on effects for the rest of the household, e.g. dietary improvements. It was found that patient participants who adapted to ensure personal, autonomous control over managing T2D tended to have the ability to overhaul their circumstances, e.g. retire early, move to the coast and so forth. Conversely, patient participants who adapted through ‘backstage’-management and co-caring tended to tinker with, or adjust, existing routines to incorporate living with T2D. The association with socio-demographic factors such as income, education suggest these factors confer advantages to these patient participants with regard adjusting personal circumstances and harnessing resources in their social contexts to adapt to living with T2D.
Recap of patients’ experiences, understanding and perceptions of successful and unsuccessful adaption to living with T2D:

Successful adaption was reported by participants as relating to overcoming restrictions through adjusting time, close relationships and use of health services in a way that resulted in routinised, sustainable practices to meet T2D-related needs.

At the patient-level, participants used retrospection, looking back in time for pay offs to gauge the success of their adaptive efforts. Patient participants also gauged the seriousness of their condition by ways they were referred within health services and encounters with healthcare professionals. As such, one measure of successful management when adapting to living with T2D was equated with appropriate and judicious use of health services. Related to this, a small group of patient participants saw successful management as having personal, autonomous control over the day-to-day management of T2D. Other patient participants equated successful management with minimising disruption to their existing circumstances. This, in turn, informed how they used health services as a resource.

Some patient participants saw T2D-related factors as an indicator of unsuccessful management of T2D – i.e. severity being associated with poor management by the individual and wasteful of scarce health service resources. However, those who lived with severe T2D frequently reported meeting T2D-related needs as restrictive and adding to their burdens which thwarted their ability to adapt in a day-to-day sense. These participants also saw few ‘pay offs’ for adapting in retrospect, and viewed often their future plans as disrupted. As such they often seek support from the healthcare professionals and health services and feel this support is lacking. Equally, poor continuity of care at the health service level was seen thwarting successful attempts to adapt to living with T2D.
4.3. Comparing and contrasting patients’ and healthcare professionals’ experiences, understanding and perceptions of adapting to living with T2D

When patient participants’ experiences, understanding and perceptions of adapting to living with T2D were contrasted with those of healthcare professionals, divergence and congruence between their approaches emerged (informing research question 3). Each theme of adaption distilled from patient participants’ accounts – developing a causal understanding, and adjusting use of time, close relationships and healthcare professionals/services – are discussed below according to divergence and congruence from healthcare professional participants’ viewpoints.

In their accounts of diagnosis/adaption, healthcare professionals saw three aspects to encouraging self-management:

4) Finding a trigger for patient action;
5) Encouraging reflection in light of clinically-recommended behaviours; and
6) Outlining the potential consequences of T2D and creating options for patients.

There was an implicit agreement and congruence in both healthcare professional and patient participants’ accounts of adaption that a partnership relationship was necessary to manage T2D in the long-term.
Divergence:

The main divergence in patient and healthcare professional participants’ experiences, understanding and perceptions of what adaption to living with T2D was. Patient participants saw adaption as a recursive process inherent to living with T2D, and the need to adapt arose with changing severity, treatments and circumstances. It was found that as patients made adjustments to their lives to incorporate T2D-related needs – in terms of time, close relationships use of services – their capacity to respond to T2D became subject to the constraints and enablers they experienced in existing circumstances, e.g. lack of healthcare professional support. Conversely, healthcare professionals portrayed adaption as a brief interlude between diagnosis and self-management. Healthcare professionals saw the outcomes of adaption as largely shaped by patient willingness to ‘choose’ to adopt and prioritise clinically-recommended behaviour.

Patient participants’ accounts of causative understandings of T2D largely portrayed T2D as a condition where their body and their social context interacted. This gave continuity to the onset of T2D in relation to other things happening in their lives. Hence, socio-contextual factors were seen by patient participants to both cause, and contribute to T2D within the body. As such, adaption to living with T2D was seen to present barriers in day-to-day life which they must manage through adjusting factors in their day-to-day lives. In fact, some patient participants gave pejorative descriptions of people living with T2D who they saw as being responsible for causing and aggravating the condition, e.g. those who were seen to be overweight. The socio-contextual orientation in patient participants’ causative accounts acted as a spur to adjust various circumstances in their lives to accommodate clinically recommended behaviours to adapt to living with T2D. In these accounts, patient participants reported factors such as poor management by healthcare professionals and uncertainty about how to respond to T2D as having aggravated T2D onset. Healthcare professional participants
discussed of T2D in clinical and physiological terms, and viewed adaption as a process of trying to achieve normo-glyceamic levels by encouraging individual behaviour change and ‘empowering’ the individual through information-giving and encouraging reflection. This notion of individual behaviour having a causal relationship with processes within the body appears to be at odds with patient participants’ causative understandings of T2D. Therefore, there is potential for misunderstanding when patients’ causative understandings encounter healthcare professional emphasis on individual behaviour change.

The issues that emerged and effected patient participants’ use of time highlighted that, for those living with severe T2D, meeting T2D-related needs was restrictive as it was time consuming, disruptive to future plans and a burdensome task. It was also found that certain socio-demographic characteristics (higher income and educational attainment) enabled some patients to adjust their circumstances to establish time-management styles that met T2D-related needs. Attaining self-management was seen largely as a matter of choice and prioritisation in healthcare professionals’ accounts. Healthcare professionals gauged un/successful self-management by patients’ ability to prioritise and choose clinically recommended behaviours, and barriers were largely seen as patient related. Conversely, in patient participants’ accounts the availability and use of time was found to be shaped by T2D-related and socio-contextual factors which shaped their options and preceded their capacity to act on their choices.

The theme of adjusting close relationships to adapt to living with T2D highlighted that people living with T2D adapted their close relationships in different ways, e.g. in a ‘backstage’, co-caring and autonomous fashion. Again, these styles of adaption were rooted in the flexibility of patient participants’ social-contextual circumstances. Patient participants who co-cared or ‘backstage’-managed T2D within the household, described adapting in a fashion that minimised disruption to their close relationships and which shaped how T2D was
prioritised on a day-to-day basis. These patient participants gauged successful management not by the degree of personal, autonomous control that adjusting close relationships engendered, but the ability to absorb T2D-related behaviours into day-to-day routines with minimal disruption. Hence, this is a divergent contrast to healthcare professionals’ emphasis on ‘ownership’ of T2D, self-directed behaviour change and prioritisation of T2D-recommended behaviours being individual choices.

Patient participants discussed *adjusting their use of healthcare professionals and health services*, using them as both a gauge and resource for adaption. One outcome of this process was that patient participants living with severe T2D frequently perceived that they had insufficient support from healthcare professionals. This meant the suggestions made by healthcare professionals about ‘owning’ and taking charge of the condition were divergent from some patients’ expectations - particularly where patient participants were seeking help due to the severity of their condition.

Some patient participants also reported a lack of continuity of care as a barrier to attainment of self-management. In contrast, this suggests that the features of the empowerment approach which healthcare professionals reported, such as working with patients’ concerns, may actually be undermined by lack of continuity of care in treatment and services. Equally, healthcare professionals showed little awareness of this lack of continuity, rather there was an expectation that ‘empowered patients’ should be able to create continuity in their care as aspect of self-managing T2D.

In patient participants’ accounts there was also a tendency to associate frequent contact with healthcare professionals and increased severity of T2D, as indicative of poor adaption and as wasteful of health resources. The majority of patient participants used health professionals and services as both a gauge and a resource for adaptive behaviours, and equated minimal use of services with successful management. Hence, it is possible that healthcare professionals’
emphasis on individual self-management of T2D is open to inappropriate interpretation by patients, in this case, with patients self-imposing barriers to self-referral.

**Congruence:**

Healthcare professional participants reported listening to patients’ concerns in order to find a ‘trigger to action’ and tailor therapeutic responses to patients needs. Patient participants also frequently cited healthcare encounters as beneficial. At this superficial level, the aim of both patients and professionals was to establish routines that facilitated successful management of T2D-related needs. Hence, both parties shared the aim of promoting successful adaption to T2D through the creation of stable routines that minimised and buffered against the ill effects of T2D.

There was congruence between healthcare professionals’ accounts of T2D causation being a process internal to the body which is amenable to individual behaviour change and a small number of patient participants’ accounts. However, patients who reported this causative account tended to have been diagnosed for a long time and discussed this as ‘being a bad patient in past’ or reported the association between behaviour and T2D onset pejoratively in other people, e.g. T2D in ‘other’ people being a result of poor dietary control.

In *adjusting their use of time* patient participants describe overcoming the initial time constraints (and reframing time dedicated to T2D) and looking back in time to gauge ‘pay-offs’ for adopting T2D-related behaviours. This suggests that healthcare professionals’ notion of allowing time for reflection enables patients to assess and appraise their responses to living with T2D, and that having pay-offs can reinforce these adaptive behaviours. Some patient participants living with severe T2D, who saw time as constrained due to mobility issues, had nonetheless begun to see day-to-day activities as signs (pay-offs) of rehabilitation and establishment of routines. Hence, where time is allowed for patients to adapt to living with
T2D, there appears to be an acceptance of benefits of clinically-recommended behaviours. However, as was the case with diagnosis, the timeframes that both patients and healthcare professionals adopt appears to be something requiring attention in healthcare encounters.

When adjusting close relationships patient participants reported that support from friends and family was beneficial and enabling. Many accounts so far have detailed co-carers being present at health appointments which facilitated T2D-related needs being understood and addressed within the household. There was congruence between both parties in the understanding that, in some cases, inviting co-carers to healthcare appointments is beneficial to adaption.

Healthcare professionals also promoted the need for ownership of T2D, and gaining skills to self-manage. It was found that some patient participants sought this style of management. Where patient participants’ sought to manage T2D autonomously, it was found that social background played a part in facilitating their capacity to do so, e.g. factors such as income, professional background, and education.

In adjusting use healthcare professionals and health services patient participants saw healthcare professionals as a gauge and resource for adaption with differential access to this resource seen as both a facilitator of, and constraint on adaption. Adaption was seen by healthcare professionals as a process of encouraging patients to change their behaviour, mainly through advice and information giving, so that patients could meet clinically recommended targets for their condition regardless of their circumstances. In both accounts of adaption there is cross-pollination between patient and healthcare professionals, where gauging and assessing health is paramount, and advice seeking and information provision is expected between the patient and healthcare professional.
In short, during the adaption process there were four key areas where differences in perceptions, understanding and experiences complicated this partnership arrangement between patients and healthcare professionals:

1) Differences in perception of the role individual behaviour and social context played causing and aggravating T2D;

2) Differences in experiences and perceptions of the malleability of time to personal will, particularly in the process of priority-making and gauging successful management;

3) Differences in perceptions, understanding and experiences of what is required in order to be self-directed (and self-managing), i.e. how close relationships and social background were seen to shape this process;

4) Differences in perceptions and understanding of the degree of support that healthcare professionals should provide.
Chapter Five – Managing Type 2 Diabetes

Patients’ and healthcare professionals’ perceptions, understanding and experiences of managing T2D

Chapter headings:

Introduction

5.1. Patient participants’ perceptions, understanding and experiences of managing T2D

5.2 Healthcare participants’ perceptions, understanding and experiences of managing T2D

5.3. Contrasting healthcare professional and patient participants’ perceptions, understanding and experiences of managing T2D
Introduction

This chapter presents findings on T2D-management and the ways it was understood and practiced by patient and healthcare professional participants. This chapter first presents the four themes that emerged from patient participants’ accounts of self-management. The chapter starts with an outline of motivations for self-management before identifying barriers and enablers and periods of disruption which impact on patient self-management. This culminates in a typology of self-management styles which are presented in part four.

Healthcare professionals’ accounts are then explored under the headings of empowered T2D management. The final part of the chapter contrasts the patient and professional perspectives illustrating divergence and congruence at the heart of managing T2D.

5.1. Patient participants’ perceptions, understanding and experiences of managing T2D

The previous results chapters illustrated the differing ways that patients receive and respond to a diagnosis of T2D and adapting their lives to the reality of living with the condition on a long-term basis. This section of the results explores self-management.

Four main themes were identified:

1) Motives for self-managing;
2) Barriers, enablers and neutralisers to T2D self-management;
3) Experiences of disruption of self-management;
4) Styles of self-management.
Each of these themes is presented in turn and illustrated with quotes.

5.1.1. Theme One: Motives for self-management

The first theme of the self-management phase of living with T2D related to the ways in which patient participants’ translated the ramifications of T2D on their day-to-day lives - as experiences of adaption - into personal reasons or motives to self-manage. Five different motives for self-managing were identified from the patient participants’ accounts of managing T2D:

a) Concern about the anticipative effects of T2D;
b) Wishing to ‘stay well’;
c) Maintaining independence;
d) Reducing the need for healthcare professionals; and
e) Improving quality of life.

Patient participants’ motives for self-managing T2D shaped how they formulated successful and unsuccessful management. It is important to note that these motives are not mutually exclusive and a combination of motivators may be in action at any one time. The five motives and associated measures of success are presented (in figure 11) and explored overleaf.
<table>
<thead>
<tr>
<th>Motive for self-management</th>
<th>Indicator of successful management</th>
<th>Indicator of unsuccessful management</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>a) Concern about the anticipative effects of T2D</strong></td>
<td>No perceived set-backs, deterioration or physical manifestations in the condition e.g. complications</td>
<td>Perceptions of set-backs, deterioration or physical manifestations in the condition e.g. complications</td>
</tr>
<tr>
<td><strong>b) Wishing to ‘stay well’</strong></td>
<td>Pay-offs, e.g. health improvements such as weight-control or stable health status</td>
<td>A perceived lack of pay-offs for self-managing</td>
</tr>
<tr>
<td></td>
<td>Reframing aspects of T2D management</td>
<td>Perceive deterioration of condition</td>
</tr>
<tr>
<td><strong>c) Maintaining independence</strong></td>
<td>No disruption to household routines and divisions of labour within household</td>
<td>Disruption to household routines and divisions of labour within household</td>
</tr>
<tr>
<td><strong>d) Reducing the need for healthcare professionals</strong></td>
<td>Minimal use of healthcare professionals</td>
<td>Increased use of health services or care-related services</td>
</tr>
<tr>
<td></td>
<td>Overcoming problems of lack of continuity of care through self-managing</td>
<td></td>
</tr>
<tr>
<td><strong>e) Improving quality of life.</strong></td>
<td>Pay-offs, e.g. health improvements</td>
<td>A perceived lack of pay offs for self-managing T2D</td>
</tr>
<tr>
<td></td>
<td>Autonomous control over T2D self-management</td>
<td>Reliance on others, incl. health professionals</td>
</tr>
<tr>
<td></td>
<td>Successes measured against non-T2D population</td>
<td>Experiencing restrictions due to living with T2D</td>
</tr>
</tbody>
</table>

Table 5: Motives for self-management with associated gauges of successful and unsuccessful management
**Sub-theme a: Concern about the anticipative effects of T2D**

The first motivator identified related to *concern about anticipated negative effects of T2D*, these included fears of symptom onset, of ‘set-backs’ and, of course, physical effects such as pain and bodily deterioration.

“Participant 1: Because you are concerned about your health and something going wrong. You take the tablets, do the diet or whatever.. Cos if you don’t you’ll be on dialysis for hours and I wouldn’t like to be like that. [...] Though it’s long term – 10, 20 years down the line.

Participant 2: I agree with him. Because the complications – although it’s long term – living your daily life, watching your diet, taking your pills and trying to keep it all under control…”

*PTFG#3 Participants -1:NB(m); 2:TH (f); 3:DC(f) - P.6; L.23.*

These anticipatory effects were often magnified where patient participants had previously seen the course of T2D in other people, most commonly family members.

“I’ve got a brother, well he died and he got an amputation in Canada. So you know these things, so you think of trying to avoid these things.”

*PTFG#3 Participants -TH (f) - P.6; L.37.*

This motive saw the adoption of self-management to avoid these anticipated effects of T2D, and was an explicitly preventative motive, with successful management framed by avoiding any (further) progression and severity in the condition.

**Sub-theme b: ‘Staying well’**

The second motive identified was maintaining current levels of health. This was frequently expressed in terms of maintaining or improving health status.
“Have never felt better, I have a better quality of life since I stopped working, and I haven't felt this healthy for a long time - compared to when I was still working. Social work is one of those jobs were you can get burnout. It happened to me, and a few of my colleagues [...] It’s because if you don’t know what is wrong with you, your quality of life is affected.”

PTI# 13 (m) - P.2; L.43

This motive for self-management – to ‘stay well’ – was often linked with perceiving ‘pay-offs’ and reframing the initial constraints the patient experienced (e.g. in relation to diet or medication-taking) as positive improvements to their lives. Also participants with complications and co-morbidities frequently accepted that a return to previous levels of health may not be possible, and adjusted to maintaining their current health status.

“ I just have to be careful with what I eat. I can’t do as much physically as I did before.”

PTI#15 (m) - P.1; L.39.

This motive for self-managing was implicitly behaviourally rewarded by following self-management behaviours in order to maintain or gain their perceived optimal health as a ‘pay-off’. Successful management was implicitly framed by the degree to which maintaining or improving health status was attained.

Sub-theme c: Maintaining independence and avoiding dependency on others

Another key motivation was maintaining independence, and avoiding dependency on others. This distinction was a personal one. By maintaining independence participants wished to maintain the smooth running of their lives without needing help or worrying others.
“I, you know, I find that my family become a bit morbid, they seem to think, how shall I put, that, they seem to think that I am special because I have this condition, I don’t have that, you know. It’s just like having a virus or like having something else, provided you take care of it, I do it all my own. I manage my blood sugar, I test my sugar myself at least once a week because now it’s very, it’s very even it never goes up or down. So to tell you the truth I have been doing pretty well on my own - they don’t need to worry”

PTI#11 (f) - P.3; L.4.

Avoiding dependency related to not having to rely on others, or increase the burden or the amount they relied on others. The participant below managed multiple conditions including T2D and experienced mobility restrictions:

“I say ‘what you put in you get out’ so I look after myself and make sure I do my sugar levels, and take my tablets. Nobody else going to do it for you are they? [...] But the thing that I want is to do a little ironing. I’ve got my washing machine in there, I sit and I wash, he [husband] irons. I get help with that. The thing I want mostly to do is a little ironing, but I can’t. I am not used to that, my mother didn’t teach me that way”

PTI#6 (f) - P.2; L.43.

This motive for managing T2D was also behavioural, but with participants being triggered to follow self-management behaviours in order to maintain independence and control over their day-to-day lives as a perceived reward. Successful management was seen in terms of the smooth running of household routines, and stable divisions of labour in the household.

Sub-theme d: Minimising use of health professionals and health services

A key motivating factor, was avoiding the use of healthcare professionals. Particular emphasis was given to avoiding hospitalisation, or nursing and residential homes in later life.
These types of care were associated with the loss of independence - but of equal concern was the perceived poor quality of health and care services.

“That’s why I do more exercise, because I don’t want to have a heart attack and end up like my Mum did, because my Mum ended up in a nursing home, and she was in and out of hospital because they weren’t looking after her properly, and I don’t want to be like that. [...] I don’t want my family to have to go through all that.”

PTI#11 (f) - P.5; L.46.

Participants also identified the need to take responsibility for their own care’ because they felt there was a lack of continuity in their care, e.g. seeing a different doctor at each check up or poor quality of services. We can see a continuity of care example where the participant states that:

“...You have got to build up trust with people and I just feel that my care chops and changes”

PTI#16 (f) - P.2 ; L.17.

Other participants were also averse to healthcare professionals, using their infrequent clinical encounters as evidence of successful self-management.

“[My doctor] knows where I’m coming from, I don’t have too much contact beyond what is necessary. We just touch base, how are you doing? Any problems? I can discuss most things with him, but don’t really need to.”

PTI#14 (f) - P.5; L.22/30.

Sub-theme e: Improving quality of life

Another motivation was improving the quality of life. Some participants sought to control their condition in ways that improved their quality of life (rather than motives rooted in fear of ill health, dependency or maintaining optimal health).
“I know I got diabetes, and I can get on and do something about it [...] They [other people living with T2D] get it in their heads that they are sick and they give up. I can still do all the things I did before, and I am not going to ... you know ... sit around feeling sorry for myself.”

PTI#10 (m) - P.2; L.36.

“That's the strange thing really, my quality of life has actually improved.”

PTI#13 (m) - P.2; L.13.

These patient participants also sought to gain greater day-to-day freedoms. This frequently involved being assertive with healthcare professionals to secure resources for self-management:

“Patients don’t always get what they are entitled to - but they often get what they deserve because they don’t question anything ... So I have got to be really assertive.”

PTI#10 (m): P.5; L.12.

“I am my own person, and the medical profession aren’t there to tell you what to do. They serve us. People forget that, and expect help ... they’re fools to themselves.”

PTI#13 (m) - P.3; L.14.

These participants also sought to maximise their existing health status and improve their quality of life through changing their circumstances. Many had retired early, some travelled and another was moving from London to the coast for health reasons:

“It comes back to quality of life. [...] where we are moving to in Lancing is very flat, I didn’t realise how flat it is. I know there are the South Downs but the actual ...where we’ll live in the town is very flat, and it will be good for walking for me, to get exercise. It’s a better way of life”

PTI#18 (m) - P.12; L.3.

This motivation is a culmination of other motivators, being both preventative and having an implicit reward system. The notion of maintaining or improving health is superseded and
expanded to include improving *quality of life* through mastery of self-management skills and acquiring the self-management resources. This involved positive comparisons with the normo-glycaemic population to gauge the success of self-management.

What is clear is that there are a variety of positive and negative motivators for self-management and two or more motivating factors may be at work simultaneously. Furthermore, criteria the success or failure of self-management are dependent on the motivations behind the self-management actions taken.

### 5.1.2. Theme Two: Barriers, enablers and neutralisers of self-management

Patient participants’ were asked what aspects of the day-to-day management of T2D they found difficult and what helped them to self-manage, and how managing T2D had impacted on their day-to-day life. Taken as a whole, these experiences showed common areas that were experienced as barriers or enablers. Patient participants reported aspects of T2D-management which had little or no impact on their daily lives (thus remaining neutral). Eight areas which were experienced as barriers, enablers or as neutral were identified and are presented in Table 6 overleaf. Each of these areas is then explored with reference to the data.
<table>
<thead>
<tr>
<th>Theme</th>
<th>Barriers experienced</th>
<th>Enablers experienced</th>
<th>Neutraliser/s</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Managing food practices</td>
<td>➢ Time needed to meet food-related needs;</td>
<td>➢ Pay-off – improvement in health is seen over time, e.g. weight loss</td>
<td>➢ Household division of labour neutralises food practices management for individual</td>
</tr>
<tr>
<td></td>
<td>➢ Eating out (Environments where personal control is limited)</td>
<td></td>
<td>➢ Having established experience of managing food practices</td>
</tr>
<tr>
<td>b) Managing medicines</td>
<td>➢ Side effects</td>
<td>➢ Pay-off – improvement in health is seen over time, e.g. increased flexibility in routine due to medication management</td>
<td>➢ No impact on diet-controlled participants but acts as incentive to keep T2D non-medicated</td>
</tr>
<tr>
<td></td>
<td>➢ Anxiety of managing and taking medication</td>
<td></td>
<td>➢ Household division of labour neutralises food practices management for individual</td>
</tr>
<tr>
<td>c) Travel</td>
<td>➢ Logistics of travel (Environments where personal control is limited), e.g. timed meals</td>
<td>➢ ‘Carpe diem’ T2D seen as a turning point and opportunity to travel.</td>
<td>➢ None reported</td>
</tr>
<tr>
<td>d) Socio-economic resources</td>
<td>➢ Living on limited income with increase costs T2D poses e.g. food</td>
<td>➢ Increased income and education facilitates access to and application of health resources</td>
<td>➢ None reported</td>
</tr>
<tr>
<td><strong>Theme</strong></td>
<td><strong>Barriers experienced</strong></td>
<td><strong>Enablers experienced</strong></td>
<td><strong>Neutraliser/s</strong></td>
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<tr>
<td>e) <strong>Work</strong></td>
<td>- Environments where personal control is limited, e.g. timed meals</td>
<td>- None reported</td>
<td>- ‘Carpe diem’ T2D seen as a turning point and opportunity for retirement</td>
</tr>
<tr>
<td></td>
<td>- Social attitudes to T2D</td>
<td></td>
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<tr>
<td>f) <strong>Exercise</strong></td>
<td>- Increased severity of T2D and poor mobility</td>
<td>- Pay-off – improvement in health is seen over time, e.g. weight loss</td>
<td>- None reported</td>
</tr>
<tr>
<td>g) <strong>Social support</strong></td>
<td>- Inflexibility of divisions of labour within the household limit capacity to self-manage</td>
<td>- Flexibility of divisions of labour within the household promotes capacity to self-manage</td>
<td>- Those seeking autonomous management where need for social support bracketed out</td>
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<tr>
<td>h) <strong>Use of healthcare professionals and health services.</strong></td>
<td>- Poor continuity of care</td>
<td>- Preparing for, and managing use of healthcare professionals and services</td>
<td>- None reported</td>
</tr>
<tr>
<td></td>
<td>- Perceived lack of support from healthcare professionals and services</td>
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</table>

Table 6: Areas of self-management and associated barriers, enablers and neutralisers.
Sub-theme a: Managing food practices

The most commonly discussed aspect of self-management was managing food intake.

Experiences of regulating food intake are affected by past experiences. The main barrier here related to restrictions imposed on food choice:

"I have to keep within the limit. So, I don’t hardly eat out, because when you eat out - there are certain things that you like to have, so there's that restriction. But, you know, even when I do things at home I have to check labels. You know, I would like to eat without being careful, you know?"

Participant #17 (f) - P.3; L.28.

Conversely the same restriction was seen by others as positive, enabling good self-management and the by-product of better health.

"I mean it’s better because I eat different because I am a diabetic [...] I feel that the diet is a healthy diet for anyone basically and it must be doing us good"

PTFG#3 Participant DC(f) - P.10; L.9/13

Where there were perceived pay-offs this facilitated continued management of food practice.

Some participants saw food management as a neutral area. For some this was due to previously healthy managed diets:

"I like the foods - so it is not a chore for me to eat well, I suppose I always have eaten well. Even when I went through rough patches in the past when I drank a lot more alcohol and smoked dope – I still ate well."

PTI#23 (f) - P.2; L.5.

Whilst for other (married male) participants it was simply because food preparation was not their concern:
“Interviewer: So has your life changed much since you were diagnosed?

Participant: Not really, just what I eat, and my wife does the cooking.”

PTFG#12 (m) - P.1; L.17.

The quotes here illustrate that fact that self-management in T2D is not universally understood or practiced and is contextually specific. The way different aspects of managing T2D were experienced— as positive, negative or neutral - related to participants’ personal experiences and circumstances, and were often context specific, e.g. restrictions experienced when eating out or travelling (discussed further below).

**Sub-theme b: Managing medicines**

Medicine management was seen by some as a restrictive process which posed barriers to routinised behaviour. This was pronounced with experiences of side effects and/or unsuitable prescriptions:

“I was only diet for about 18 months and then went on to tablets, all sorts of different tablets they tried and eventually in 1999, I was on steroids for a time [...] If I’m feeling well I don’t worry about it. You know that you have to have your injections before breakfast and then you’ll be okay. If I am going through a lot of hypos, it comes in little clusters, then I get a bit more, oh should I do another blood sugar. I carry glucose with me and in the car. If I go high I don’t worry too much really because I tend to think that I’m not going to go down that low when I’m out and about or anything. When I last went [to the GP], they just told me to increase my night time insulin which I did and I had a hypo that same night so I thought that’s daft, I’m not doing that and so I didn’t go back.”

PTI#16 (f) - P.1; L.19/ P.2; L.11.

Even where medication taking was relatively straightforward it could engender anxiety:

“This is my tablets, watching your blood sugar – you can’t help worrying its human nature.”

PTFG#3 Participants NB (m) - P.6; L.23.
Many patient participants who were veterans of T2D-management reported gaining a steady regime of medication management with time - which led to improvements in their lives:

“It’s a case of trial and error. When you start you have to check your sugar levels quite a lot to find what puts things up and what puts things down and then you can get into a routine with it, you get a level and if you have more of what you are not supposed to have, you take more insulin but you have to gauge that and work it out yourself. After a while you can just tell which way it’s going, up or down, and after a while, you just get on with it.”

PTI#10 (m): P.2; L.17.

These improvements came not only from feeling healthier and the gains in self-management this facilitated, but from no longer finding the process of medication management problematic:

“Well, I thought there must be something not working. My tablets probably want changing or something and that’s the time I went back to the doctor and he increased my metformin, so that’s one less thing. If you keep it under control it is easier to push it into the background.”

PTFG#3 Participants -TH (f) - P.6; L.37.

Pay-offs for medication management related to medications allowing more flexibility in day-to-day routines and improving health status.

**Sub-theme c: Travel**

Travel was frequently reported solely as a restriction - as it represented a disruption to the flow of day-to-day routines, detailed planning, and environments where personal control of resources to self-manage were limited.
“I was going to Australia last year and was scared of flying – not the flying it was about travelling with my condition and travel insurance. I have to eat on time, and you look like you are making such a fuss on the aeroplane.”

PTI#22 (f): P.3; L.21.

“If you put your insulin in your case then it will freeze in the hold and then it’s no good. Especially now with terrorism, you really have to have a letter with you from the doctor or the hospital. [...] And with the meals, I take things with me but I’ll also speak to the stewardess and they will usually find you something.”

PTI#10 (m): P.3; L.30.

Even shorter car trips could be stressful and tiring, particularly for those living with severe T2D:

“About four years ago I learnt to drive and I did it because I realised that I was developing a problem but now I’m getting to not like driving - partly because I get so tired. So social things, like going to Lancashire and things like that, even to Suffolk, I regard that now as a long trip, and I’m not very keen on it. Well I wouldn’t drive more than two hours.”

PTI#2 (m) - P.9; L.31.

Whilst the process of travel itself was experienced as disruptive and restrictive for all participants, this did not stop some participants travelling and enjoying the trips. This was common for those who saw onset of T2D as a turning point, and ‘seized the day’:

“.... I go travelling a lot now, I've been to India, South Africa, the States... That's the strange thing really, my quality of life has actually improved.”

PTI#13 (m) - P.2; L.13

Sub-theme d: Socio-economic resources

Only a handful of participants discussed the financial costs of living with T2D as a constraint to self-management, this included discussions of living on a limited income (pensions):
“Well there's also, I've got a problem with money. We need to be careful about what we eat, which costs money and there’s not a lot to go around. I get my, I get my allowances which I'm entitled to but having spent years overseas and coming back, money which I should have had I haven't because things went wrong - so we're just living on my wife's.”

*PTI#7 (m) - P.7; L.20.*

In discussing how to successfully manage T2D, one participant, suggested that coming from a wealthier background may confer advantage with healthcare professionals and facilitate self-management.

“My wife and I being professionals, semi-professional people, we've always been reasonably good at finding information so far. The NHS is available to everybody. And I think of the various consultants we both have to go to, and see that if you've informed yourself, their response will be ... to you ... will be better.”

*PTI#2 (m) - P.7; L.39.*

In this instance it is not the wealth that is the key factor so much, as the social (class) status and intellectual capital that comes with it, which facilitates the ability to secure resources needed to manage T2D.

**Sub-theme e: Work**

Participants spoke of their current and past experiences in the work environment; all reported constraints within the working environment mainly relating to the need for timed, regular eating habits:

“So I get to work and you I am almost hypo, so you have to have something then and a warm up drink and they didn’t seem to understand that. Then halfway through my shift I’d want my dinner because of my tablets, but then later on towards the end of the shift you’d almost want another sort of tea break [...] They also didn’t understand that kidney related disease, you have to go more to wee don’t you? So, they complained because I was going to the toilet too much.”

*PTI#18 (m) - P.3; L.6.*
The participant below discusses the difficulty of managing T2D in socially-negotiated environments, e.g. having timed breaks. She also notes a lack of understanding of the needs of those living with T2D.

“One of the bosses turned round to me and said, none of us have had lunch today. Well that’s not the kind of answer you expect. Would they say that to somebody with cancer?”

PTI#2 (f) - P.7; L.13.

A few participants also felt there was little provision for people living with T2D in working environments, unlike the provision other long-term conditions and disabilities.

**Sub-theme f: Exercise**

Older participants’, and participants’ living with co-morbidities and complications of T2D often reported difficulties in exercising regularly:

“I tell them [healthcare professionals] I can’t do it [exercise]. I have arthritis so it’s hard for me to even get out this chair sometimes. I watch that I don’t do too much and go hypo, or have a fall. I can walk, so they say take a walk, but I just get tired, if I’m not feeling good - I get too tired.”

PTFG#3 Participant (CC) - P.9; L.19.

Many saw T2D as having reintroduced them to the need for exercise, and took great pleasure in the activity. The participant below, for example, had taken up exercise at a local community centre, and had then been asked to teach a class.

“I’m not really ill am I? I don’t class myself as ill. I just get on with it. And things have gotten better, I wouldn’t have my exercise if I hadn’t have got diabetes. I’ve learnt so much”

PTI#11 (f) - P.4; L.26.
Similar to managing food intake, people also saw gains in the short-term from exercising regularly, e.g. weight loss:

“I’ve been doing a bit of exercise and lost a bit of weight, so it’s gone down, so I’m pleased about that.”

PTI#16 (f) - P.4; L.26.

The framing of exercise as a positive aspect of self-management was particularly common in diet controlled participants, and those diagnosed through screening.

**Sub-theme g: Social support**

A few participants discussed personal constraints to receiving support from family and friends, the main constraint being that they did not wish to be a burden to others, or cause their family worry. This related closely to the integration of T2D management and division of labour within the day-to-day routines of the household:

“He don’t like it, because I eat a lot of salads and that, and my husband doesn’t like salads. So I just do his and then I do mine.”

PTI#10 (m) - P.7; L.23.

“There isn’t anything wrong with him [husband], he should do more!”

PTI#1 (f): P.3; L.41.

Also we have seen in the previous section that co-caring with a partner or loved-one often lead to arguments and uncertainty about recognising symptoms, and best courses of action to take:

“Participant 2: He used to suddenly get this bad temper and this bad mood for nothing at all, it just used to come from nowhere, no particular reason ... When he got bad tempered like that... It’s like he’s not right. It is irrational, that mood.”
Participant 1: Can’t I have a bad mood?

Participant 2: No, this was a dark mood. He’d start to complain, and was very restless, stamping about shouting. I’d go and do the ironing or something, get out from under his feet. It would pass, you know.

Participant 1: If you weren’t fretting over me. I would have checked my blood I know...

PTI#18 (m = R1 + wife = R2): P.3; L.43.

As we saw in the adaption section, some participants explicitly hid the visibility of their T2D-related maintenance tasks with the tacit acquiescence of the family. The support of loved ones was a frequently reported as an enabler of successful management of T2D. This was particularly common in severe cases of T2D as it allowed people greater independence within the home, and created a buffer of routinisation.

“If I didn’t have him [husband] I don’t how I would manage in here.”

PTI#6 (f): P.2; L.45.

As we have seen in adaption (and discussed further below). Where autonomous control of T2D was sought by the patient participant, the effect of social support was in effect neutralised.

Sub-theme h: Health professionals and health services

Poor quality of care and poor continuity of care were reported as strong constraints to achieving self-management:

“You have got to build up trust with people and I just feel that my care chops and changes”

PTI#16 (f) - P.2; L.17

“They’ve [health professionals at local GP practice] changed so many. It’s a group practice – about eight of them and they’re all constantly changing. [...] They said ‘Come and see the nurse’. She handed me a book about diet and that was all I’ve ever had in the way of advice.”

224
Many participants rejected the notion that T2D management was shared with health professionals, arguing that they alone carried the larger burden of care – often viewing this lack of support as a barrier to their ability to self-manage:

“I know I need to lose weight. I don’t need hospital staff to tell me I need to lose weight and making me feel it’s all my fault. ‘Yes, you’ve made a start on losing weight but we mustn’t get complacent about this. We’ve still got a long way to go’. IT’S ME THAT’S BEEN STRUGGLING TO LOSE WEIGHT, NOT WE.”

At the same time, participants did report instances of healthcare professional support enabling self-management of T2D and the importance of a good relationship with healthcare professionals facilitating successful self-management:

“My first consultant was very good for many years, then I had a new one who didn’t seem to listen, or support me. At that time I was concerned that I had poor control and that it was affecting my eyesight, but he didn’t seem to take me seriously. My eyes weren’t being monitored adequately at the time which added to my concern, so I asked to be transferred to [Name of Hospital], and I feel much more supported there, and listened to. Dr. [Name] is a very good doctor.”

Many patient participants valued the support, advice and resources they could get from healthcare professionals. As the bulk of T2D management was carried by patients, the majority of participants reported the clinical encounter as a key task to be managed and maximised as part of living with T2D:

“One thing I found useful was writing down questions to take to the doctor, and it seemed a strange thing to do, but... I would never go a meeting unprepared, or without a list of things I needed to know.”

Similarly, some patient participants saw healthcare professionals as a means to an end.
“People say to me, oh I go there, they [healthcare professionals] are ever so nice there. I couldn’t care less if they are nice to me or not, they can be as nasty as they like, as long as I get the best treatment. I’m not bothered about personalities.”

PTI#10 (m): P.6; L.23.

These patient participants argued that the gatekeeper role that health professionals adopted in relation to health resources was a barrier to self-management. These participants saw assertive self-management as a means to challenge healthcare professionals to facilitate self-management of T2D:

“The National Health and all public services are very good at fobbing you off but when you say this is what I want and this is what I’m entitled to they always back down, always. ”

PTI#10 (m) - P.7; L.23.

Again, these were wealthier, more educated patient participants who had been living with T2D in excess of 3 years.

What is apparent within the accounts here is that there were no universal barriers and/or enablers (or neutralisers) to self-management, rather the types of barriers and enablers were realised by patient participants’ applying T2D-related behaviours within their day-to-day circumstances, i.e. their social contexts. Equally, the impact of living with T2D could be neutralised over time, by support within the household and social factors such as income and education.
5.1.3. Theme Three: Experiences of disruption in self-management

In line with the continuous process of adaption, participants reported the actual process of self-management as punctuated by periods of uncertainty and apprehension which acted as barriers. Periods of uncertainty occurred where aspects of their routines were adjusted, and were common. They continued on from the forms of uncertainty identified in previous results chapters. These were:

Sub-theme a: Symptom uncertainty

Symptom uncertainty caused disruption where symptoms were experienced and ascribed to another illness, or not recognised as a symptom, triggering a search for clarity.

Sub-theme b: Response uncertainty

Response uncertainty was a disruption when a (novel) symptom was recognised but there was uncertainty about: a) the seriousness of the (often new) symptom and b) whether the symptom warranted medical intervention or could be dealt with by the individual.

Sub-theme c: Co-caring uncertainty

Co-caring uncertainty was identified as arising from disagreements between the person living with T2D and their spouse or co-carer about signs and symptoms, and the best course of action to take in managing T2D.

Sub-theme d: Information uncertainty

Information uncertainty was experienced in relation to the validity of different types of information. This was common where information and advice had changed with new developments in treatments or was contradictory to patient understanding. Information
uncertainty also emerged where there was contradictory advice, from different professionals and/or other sources of information such as that found on the internet.

“They tell you one thing one day, and another thing another.”

PTI#9 (f) - P. 3; L.13).

Sub-theme f: Apprehension

Apprehension occurred where the ramifications of T2D become a source of constant worry and fear for the patient, and they become preoccupied with these ramifications. One example frequently discussed was where patients reported repeatedly monitoring blood with a hand-held meter. This type of apprehension was reported as fluctuating over the course of the illness, and described as usually clustering around diagnosis and symptom-events:

“I get frightened by the appearance of another consequence of the diabetes – neurological, heart, kidneys. Then I tighten my control, and much more severe with diet. I go without some foods, and I don’t I feel guilty and keep checking my blood. Inevitably this lapses between whiles.”

PQn#6: pg 3.

Participants were acutely aware of this in themselves and others:

“I remember going to one of the meetings at the library and this[ ...] gentleman was sitting next to me and he told me he tested his blood every day and he got upset when it wasn’t as it should be and I thought, I don’t want to go down that road”

PTI#4 – P.3, L.31

The majority of participants referring to this apprehension said they had personally experienced this type of apprehension (n=5 of 8), and it was also reported in others. These periods of uncertainty and apprehension were significant to self-managing T2D as they were usually described as: 1) a trigger for information-seeking, 2) a trigger to adapting to a new
manifestation of T2D, or 3) were also interpreted as signs that T2D was being unsuccessfully managed.

5.1.4. Theme four: Styles of self-management

In response to self-management questions, patient participants described T2D management using both their present and past experiences. Patients were asked about how they used health information, it was found that the ways patient participants use information\(^1\) was related to their self-management style. Patient participants coalesced around six distinct styles of T2D self-management. The styles identified were:

a) Self-managing T2D through routinisation
b) Self-managing T2D as a burden
c) Self-managing T2D as keeping T2D at bay
d) Self-managing T2D through delegation
e) Self-managing T2D through co-management
f) Self-managing through autonomy

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Sub-theme a: Self-managing T2D through routinisation

Self-managing T2D through routinisation involved developing routines that provided a buffer against the ramifications and/or potential progression of T2D. As such, routinisation was a key building block of T2D self-management.

“Most of the inconveniences become less obvious to you, you stop noticing them. They become part of your life, like catching the train in the morning, or brushing your teeth. It becomes part of your life. [...] I have a plan and a routine.”

PTI#14 (f) - P.3; L.44.

Contrary to the apprehensiveness described earlier, participants did not over-regulate their behaviour as they were confident in the buffering effects of the routine.

“What I am taking away from having diabetes is how to care for oneself, the importance to stick to a routine, to check your routine.”

PT I# 5 (m) – P. 2; L.25.

 “[T]he diabetes is Type2. And I don’t have to take the tablets, but that doesn’t mean I don’t have to do anything. But I exercise now, swim 2-3 times a week. I go for two walks, two half hour walks a day. I have to watch my weight, because that isn’t good for me.”

PTI#21 (m) - P.1; L.20.

In periods of disruption, these patient participants sought out didactic information to provide a baseline of knowledge about T2D and management of the condition, upon which future decisions and behaviour could be based. Minimal use was made of this information beyond a basic understanding of the disease.

“I pick up the leaflets, I’ve read them, I know them almost back to front. I know what I should do and what I shouldn’t do.”

PTI#6 – P.9; L.25.
This quote illustrates this basic type of information use. No further information was sought, and there was no expectation that any additional information needed to be actively sought at a future time as was the case in other self-management styles.

Patient participants who self-managed through routinisation (solely) equated being satisfied with aspects of their self-management being routinised in a way that minimised disruption to their life.

“I still get around, still do my work, and I can still look after myself I suppose. I go to sleep and when I wake up - I’m the same... You have to get on.”

PTI#9 (f) - P.3; L.4.

As such, routinisation of self-management is attained as a style of self-management in and of itself (as was the case with seven, n=7, patient participants here), mostly those who were newly diagnosed (within 1 year).

What is important is that routinisation also formed the basis of, i.e. was adjunctive to, the other styles of self-management discussed below. The main motives of having routinised management arrangements were wishing to stay well and avoid the anticipative effects of T2D. Also use of information was didactic. The styles of self-management below build on routinisation but differ from pure routinised self-management in motive, divisions of responsibilities, use of information and gauges of un/successful management.

Sub-theme b: Self-managing T2D as a burden

For some participants day-to-day tasks were perceived as burdensome. This was largely due to patients perceiving the manifestations of T2D as irreversible, or immune to self-directed care activities.
“[A]s a man, feel absolutely useless. I feel first of all - I'm now impotent as well, [...] I had all their complete list of things, I had the testosterone patch, I had Viagra, I had the urinal injection to the penis, I had the injections around the penis, I was there for about a year and a half, and nothing worked. So you know, I can't do anything of a sexual nature, which frustrates me. ”

*PTI*#7 (m) - P.4; L.20.

People managing T2D as a burden developed a routine to respond to T2D - but believed (or hoped) that more could be done clinically to prevent further deterioration. In seeking help their motive was to maintain a current level of health, avoid being too dependent on others and maintain existing independence. Key to this belief was that more of the burden and responsibility of care could and should be borne by others - e.g. referral to secondary care, or better medication would enable to them live better.

“When you start to, when I started on tablets... and because my blood sugar keep getting higher, I want you know, positive treatment for it, but they increased the tablet, they only increased my tablets from year after year until... I had a heart problem, I've now got a pacemaker and I have to do all of this [manage diabetes].”

*Patient Interview Participant #20 (f) P.1, L.50*

This group of participants also sought didactic types of information, and felt that healthcare professionals should use *their knowledge* to manage T2D. Participants experiencing self-management as a burden perceived aspects of treatment as beyond their control and responsibility (i.e. outside their ability to respond), or had *not* traditionally been their responsibility (and hence, that they have been *burdened* with managing aspects of T2D):

“And they [healthcare professionals] just keep saying: I can do this or do that and your blood sugars are all over the place - and asking me what I am going to do about it. And they are supposed to tell me!”

*PTFG#2 Participant - ME (f) - P.6; L.21.*
Notions of successful and unsuccessful management were closely related to the support and resources they received, and support and resources sought – as well as how these participants divided responsibility for managing T2D. Although maintaining independence and avoiding dependency was a key motive to self-management, a perceived lack of support and resources available to self-manage was seen to be a barrier on their ability to be independent.

“...I've now got a pacemaker and I have to do all of this [manage diabetes].”

Patient Interview Participant #20 (f0 P.1, L.54.

Six (n=6) participants, three of whom were restricted in mobility and the ability to live independently, discussed self-managing T2D as predominantly an experience of being burdened, and saw additional support and resources as the solution. The four (n=4) oldest participants interviewed were in this category, and all had low incomes (less than £10k p.a.) and four (n=4) managed co-morbidities. This suggests that age, severity of T2D and income may be key factors shaping this style of T2D management.

Sub-theme c: Self-managing T2D as keeping T2D at bay

For participants within this sub-theme, routines were followed and the aim of self-management was to keep the progression of symptoms and complications at bay, i.e. to keep T2D consequences at bay.

“I think it helps to see other people, because as I said mine is not so serious, so at least, when you listen to other people, then you probably know what to expect, and to see whether you can avoid some of the things.”

PTI#9 (f) - P.3; L.21.
Amongst these patient participants, there was also a tendency to measure successful self-management by comparison with others living with T2D,

“I’m alright, healthy even... Just wear and tear you’d expect, and if you stick at it [diet] you don’t have no worries”

PTI#21 (m) – P.3; L.40.

“For me the worst thing would be to go blind, because I haven’t kept my blood sugar in check and it creeps up”

PTI#9 (f) – P3; l.32

This style of management was common in those with hospitalisation diagnoses, who had subsequently recovered. These patient participants often wished to attain a previous health status, avoid the anticipative effects of T2D, and minimise use of healthcare professionals. Participants who were diet-controlled and/or currently experienced no symptoms or complications also showed this style of self-management.

“Of course, at some point in the future I may need insulin injections – which, again – I am pushing into the background because fortunately it isn’t happening right now. I just do what I have to, and tune the rest out.”

PTFG#3 Participant #3 (f) - P.4; L.18.

The style of managing T2D as by keeping it at bay was reflected in their style of information use. These patient participants collected information either for reference, or to inform their response to future events or symptom change.

“If it was needed I use it, if it is not needed I’ve got a box with all the information in it so I can refer to it if necessary. If I get a cold for instance I will look up to see what I should be doing or shouldn’t doing and I find them very useful [...] I refer to it if I need to.”

PTI#4 – P.3; L.21.

Information was not applied pre-emptively to inform day-to-day responses rather, stored, against future needs.
Although not tallying with specific socio-demographic characteristics, this style of T2D management was predominantly reported by people (n=9) who had been diagnosed for over a year, and those who had been diagnosed with T2D as a result of hospitalisation. Although these participants used their encounters with healthcare professionals and use of health services to gauge self-management success (i.e. no progression in severity or symptoms), their motives for self-management were informed and reinforced by minimal use of healthcare services i.e. evidencing that T2D has been kept at bay.

Sub-theme e: Self-managing T2D by delegation

This style of self-management emerged where certain aspects of managing T2D were passed on by patient participants to somebody else. Management of T2D is seen as more appropriately dealt with by a delegate (for safekeeping) – for example, where the spouse/co-carer takes charge of cooking, or made sure medicine was taken appropriately. Male participants tended to dominate this category with four out the five participants (n=5) in this sub-group being men.

“I have to eat the right food but I don’t drink, I don’t smoke, I have cut down on my sugar, I have cut down on my starch and I eat a lot of fruit […] When I go to the doctor they check my blood sugar and ask how I am coping with the diabetes. My wife cooks for me and checks if I have taken my tablets every day.”

PTI#9 (m) - P.2; L.11.

Health professionals were also used to safe-keep certain aspects of T2D management:

“I am coping a bit at the moment, but as far as you say about the blood testing, I think it will give me more stress to do all this testing than not do it. And I have a really good diabetic nurse at the doctor’s surgery who takes my bloods and puts me on the right road most of the time. And she seems to be quite happy with the way I am progressing.”
PTFG#3 Participant DC (f) - P.6; L.44.

The motives of these participants were similar to those in the last group in relation to maintaining current health and concerns about anticipative effects, but the method was different with key aspects of care delegated to others. Participants also sought to maintain their independence, and disruption to the delegated routine could compromise this.

“If I didn’t have him [husband] I don’t how I would manage in here.”

PTI#6 (f): P.2; L.45.

The main difference between managing T2D through delegation and by keeping T2D at bay was that a delegated other is tasked with ensuring the routines of T2D are met, and providing there are no disruptions in this arrangement, T2D is seen as being managed successfully. Participants with this style of self-management also managed health information for reference purposes only, referring to health information as, and when, needed. There is also a continuation of co-caring arrangements established during adaption. Un/successful management and constraints are measured according to whether existing divisions of labour and routines have been disrupted.

Sub-theme f: Self-managing T2D through co-management

This style of T2D management related predominantly to the quality of relationships with healthcare professionals as patients were usually self-directed. Managing T2D through co-management entailed patient participants being able to discuss the ramifications of certain treatment options and self-management activities with healthcare professionals to inform their self-management. Participants also established clear demarcations of responsibility with
healthcare professionals. Patient participants engaged in co-management reported benefits where healthcare professionals listened to their personal concerns and worked with them to get appropriate care and treatment options:

“I have great confidence in my nurse - mostly because she agrees with me anyway! No, she does give me advice and confidence as well. We have a bit of a laugh and she said there is obviously something wrong with you when you can’t take this drug and you can’t take that drug and we thought it would all be easy and of course it’s not been as I have had a few problems with the drug. But no, she comes up with recommendations and suggestions and we work it out really.”

PTI#4 (f) - P.5; L.6.

Motives for self-management within this group were: to stay well; improve health; and reduce the need for healthcare professionals involvement.

These patient participants also described actively seeking out information to enable them to better self-manage their condition. Information was used both as a tool for planning disease and symptom responses, as well as for planning prevention strategies.

“Things like, even a tin of baked beans has sugar in it so you need to consider that. [Information] It is very good, and goes into the details of what has caused it, and what the symptoms are and what you can do to stop your sugar going up.”

PTFG#3 Participant DC (f) – P.14; L.39.

The participant above uses the seemingly small piece of information about food labelling to relate it to how such information can help with their understanding of the disease as a whole. So the information is assimilated within the person’s overall understanding of the disease.

Only six (n=6) of the thirty-seven (n=37) patients interviewed reported experiencing this type of relationships with healthcare professionals.
Patient participants often reported wanting to co-manage with healthcare professionals, but felt that professionals didn’t listen or were dismissive of their concerns, and/or there was a lack of continuity of care to allow this type of arrangement to occur:

“I just, I just feel that, you know, when I go to the hospital or to my doctor I just feel that I should be seen by somebody. I mean I should, I know it’s maybe asking for too much but I should not be seen by a different doctor every time because it doesn’t give a full understanding of my condition. They start you back from the beginning and it annoys me.”

PTI#20 (f) - P.4; L.32.

A number of participants in this grouping reported how they originally struggled to secure co-management arrangements with healthcare professionals. However, they were able to independently acquire continuity of care. By researching and becoming well-informed about T2D and different types of services, these patient participants gained continuity through relaying what they knew about their condition information across services and healthcare professionals. This ensured they were taken seriously and that information was up to date:

“I think the reason I’m not worried about the diabetes, because there’s more information available about the diabetes. [...] I am much luckier than five, six years ago. I can say, you know, I read this and then they have to take you seriously, don’t they. They do at [Name of Hospital], because if you know what you’re talking about its difficult for them to get rid.”

Patient Interview Respondent # 18 (m) – P.3; L.1.

This often led to participants seeking information to assess the array of clinical options open to them.

“All medicine is forever changing and what’s believed at one point can be overturned by new research and if you don’t know about it, you will carry on in the same old way perhaps creating problems, and you can’t assume what’s good for one is good for another. It’s a juggling act. [...] You need to keep your knowledge up to date. If your knowledge is stuck at some point in the past you
can’t assume that your doctor is up to speed, you just can’t. You need to know what is available, and how it could benefit you.”

PTI#7 (m) – P.7; L.17.

Here, information was used both as an individual tool and as a way of informing others. Information is not only stored and assimilated, but has also accommodated the information in the general schema of their knowledge surrounding illness in general.

The practice of co-management styles of self-management came with time - as all reporting this style of self-management had been diagnosed a year or more. This style of self-management is the one which most closely reflected the tenets of the empowerment approach, but only a small minority of participants used this style.

**Sub-theme g: Self-managing through autonomy**

Patient participants who self-managed T2D autonomously managed T2D in a style that ensured their autonomy was maintained. These participants were often calculative in their assessment of, and ability to, respond their own T2D needs.

“You see some of the older people at the participation group, and they don't really understand the information or know what they are doing, and they ask the same questions every week ... it's just not getting through to them. For me, personally I have never felt better. Insulin gives me more control, and means I can do more than sit around worrying about diabetes. [...] So, that’s what you have to do, you have to grab the reins.”

PTI#14 (m) - P.4; L.32/38.

Those self-managing T2D autonomously described having to be assertive with healthcare professionals. This allowed them to develop ways to gain leverage over care and treatments
which allowed more direct control over their T2D. This involved managing T2D strategically, and keeping abreast of latest treatments and research into T2D services:

“I have excellent control and have had excellent control since the beginning. All illness creates problems of one sort or another so if you want to cut down on the number of problems you need to keep your knowledge up to date. If your knowledge is stuck at some point in the past you can’t assume that your doctor is up to speed, you just can’t.”

PTI#10 (m) - P.7; L.18.

Like those who managed T2D through co-management, patient participants managing T2D through autonomy used information to assess and challenge their clinical options. This grouping sought to improve the quality of care provided by others and the capacity to self-care. At this level information seeking was both self-directive and assertive.

“They [professionals] seem to forget that the National Health is a service for patients, it is not a charity. You are entitled to it but it is up to the patient to make sure they get the service. If you have to go to the chief executive to get it, that’s what you should do. You won’t get anywhere if you’re passive...I always say, you are entitled to that, demand it”

PTI#10 (m) - P.3; L.21.

Information was used not just to ensure that appropriate and up-to-date care was received, but that this care was of the highest quality. Information is not just stored, assimilated and accommodated information about diabetes per se. It is linked it with knowledge relating to successful health system use.

“The cleverest person in the world can always learn something, I’m not one of those people who says I know it all therefore I don’t need to look any more. I am not like the doctor with the bit of paper who says I’ve learned it. Well new things come along. [...] The National Health [Service] are very good at fobbing you off – but when you say this is what I want, and this is what I’m entitled to they always back down, always.”
Here, we can see that managing healthcare professionals and services is seen as part of managing T2D, and information is used to leverage not just clinical options available but entitlement to the best quality care. Healthcare professionals were seen as a means to an end, and contact with them was minimized, and this lack of contact in itself was used as a measure of successful self-management.

“[My doctor] knows where I’m coming from, I don’t have too much contact beyond what is necessary. We just touch base, how are you doing? Any problems? I can discuss most things with him.”

Self-management was also conducted strategically and to ensure that outcomes reflected their personal needs, improved quality of care and quality of life. The aim of self-management was frequently to engage in activities that the non-diabetic population engaged in, i.e. to overcome the ramifications and restrictions of T2D.

“People’s jaws drop when I tell them that I drink wine and eat chocolate cake. It’s a revelation to them, some are new to injecting, and haven’t come round to it. My doctor is in despair at my experiments, I find that the dosage is important and how rapid the insulin is, but you can inject in different places for different effects too.”

All of the patient participants falling in this category (n=4) had professional qualifications (but not all with degrees and professional qualifications fell into this category). Two (n=2) of these participants also had healthcare professional backgrounds. All had been diagnosed 2 years or more, and three were insulin-dependent and managed other illnesses. These four patient participants had the highest incomes of all those taking part in the study. This
suggests that this style of T2D self-management was facilitated by income and the access to social and personal resources that this conferred.

**Overview of styles of self-management**

The results here show that attaining a routine is the foundation stone for all types of self-management. How and why the routines are maintained and who is involved in the self-management process varies across groups. Establishing a routine is often the first stage for newly diagnosed participants and once established, motives for self-managing, resources available and the circumstances that people find themselves in, all shape the management styles adopted and the ways in which information is used. The figure overleaf charts this:
<table>
<thead>
<tr>
<th>Style of self-management</th>
<th>Motives for self-management</th>
<th>Gauges of un/successful management</th>
<th>Role expectation/s</th>
<th>Health information use</th>
<th>T2D &amp; Socio-demographic characteristics</th>
</tr>
</thead>
</table>
| Self-managing T2D through routinisation (n=7) | ‘Concern about anticipative effects’ ‘Staying well’ | **Successful:**  
1) No perceived deterioration, pay-offs for self-management  
2) No disruption to routine  
**Unsuccessful:**  
1) Perceived deterioration, lack of pay-offs for self-management  
2) Disruptions in stable routine | None reported | Information used didactically | Newly diagnosed ≤ 1 year |
| Self-managing T2D as a burden (n=6) | ‘Concern about anticipative effects’  
‘Maintaining independence’ | **Successful:**  
1) No perceived deterioration, or pay-offs for self-management  
2) No disruption to routine  
3) Support from healthcare professionals  
**Unsuccessful:**  
1) Perceived deterioration, lack of pay-offs for self-management  
2) Disruptions in stable routine  
3) Lack of support from healthcare professionals | Regular help and support from healthcare professionals to enable self-management | Information used didactically | Advanced age 70+  
Living with severe T2D/complications  
Low income ≤ £10 k p.a.. |
| Self-managing T2D by keeping T2D at bay (n=9) | ‘Concern about anticipative effects’  
‘Staying well’  
‘Reducing need for healthcare professionals’ | **Successful:**  
1) No perceived deterioration, or pay-offs for self-management  
2) No disruption to routine  
3) Minimal use of healthcare professionals  
4) Downward comparison with others living with T2D  
**Unsuccessful:**  
1) Perceived deterioration, lack of pay-offs for self-management (T2D not kept at bay)  
2) Disruptions in stable routine  
3) Increased use of healthcare professionals | Minimal contact with healthcare professionals validates self-management activity (T2D was kept at bay) | Information used for reference | ≥ 1 year since diagnosis  
Diagnosed as a result of hospitalisation and screening (often asymptomatic) |
<table>
<thead>
<tr>
<th>Style of self-management</th>
<th>Motive/s for self-management</th>
<th>Gauges of un/successful management</th>
<th>Role expectation/s</th>
<th>Health information use</th>
<th>T2D &amp; Socio-demographic characteristics</th>
</tr>
</thead>
</table>
| Self-managing T2D through delegation  
(n=5) | ‘Concern about anticipative effects’  
‘Staying well’  
‘Maintaining independence’ | **Successful:**  
1) No perceived deterioration, pay-offs for self-management  
2) No disruption to routine  
**Unsuccessful:**  
1) Perceived deterioration, lack of pay-offs for self-management  
2) Disruptions in stable routine | Minimal contact with healthcare professionals validates self-management activity | Information used for reference | Gender (predominantly males) |
| Self-managing T2D through co-management  
(n=6) | ‘Concern about anticipative effects’  
‘Staying well’  
‘Maintaining independence’  
‘Reducing need for healthcare professionals’ | **Successful:**  
1) No perceived deterioration, or pay-offs for self-management  
2) No disruption to routine  
3) Minimal use of healthcare professionals  
**Unsuccessful:**  
1) Perceived deterioration, lack of pay-offs for self-management  
2) Disruptions in stable routine  
3) Lack of continuity care  
4) Increased dependency on healthcare professionals | Minimal contact with healthcare professionals validates self-management activity  
Individual becomes source of continuity in care in T2D management | Information used to assess clinical options | ≥ 1 year since diagnosis |
| Self-managing through autonomy  
(n=4) | ‘Concern about anticipative effects’  
‘Staying well’  
‘Maintaining independence’  
‘Reducing need for healthcare professionals’  
‘Improving quality of care’ | **Successful:**  
1) As 1-4 above  
2) Autonomous control over T2D self-management  
3) Successes measured against non-T2D population | Minimal contact with healthcare professionals, a means to an end  
Self-directed, autonomous control of T2D  
Strategic management of T2D behaviours | Information used to assess clinical options  
Information used to lever greater quality of care | ≥ 2 year since diagnosis  
Increased income ≥ £28k p.a.  
Professional and degree-level qualifications  
Insulin-controlled  
Co-morbidity (few) |

Table 7: Styles of patient participant self-management with associated motives, indicators of un/successful management, role expectations, style of information use and socio-demographic characteristics.
Overview of patient participants’ perceptions, understanding and experiences of managing T2D

The results in this section demonstrate the socio-contextual nature of self-management in its established phase, building on the findings in relation to diagnosis and adaption processes. What is clear is that motivation for self-management effects measures of success and failure from the perspective of the patients. Multiple styles of self-management were found which were shaped by severity of T2D, types of uncertainty patients experience, the expectations patients had for healthcare professionals, support within the household as well as socio-demographic characteristics patients brought to self-management. Criteria for un/successful self-management are not, therefore, universal, but contextually driven. Furthermore (in response the research question 2) it is clear that barriers and enablers are not specific to areas of self-management – such as food management – but to the context within which this area is managed. Patient, healthcare professional, health service and social contextual level barriers and enablers were experienced across all areas of self-management.
5.2. Healthcare professionals’ perceptions, understanding and experiences of managing T2D

Participating healthcare professionals were asked a series of questions relating to what constituted un/successful management of T2D, and issues they face in managing T2D on a day-to-day basis. T2D management was almost wholly discussed within the empowerment paradigm. This is covered under one main theme as empowered T2D-management. This was multi-dimensional, and four sub-themes were found:

a) Empowering patients;
b) Empowerment as practice;
c) Empowerment as healthcare delivery; and
d) Empowerment as response to social change;

The manner in which healthcare professional participants fashioned these interrelated themes into a singular mode of empowered self-management was found to underpin their approach to, and ethos for, managing T2D.

5.2.1. Theme One: Empowered T2D-management

Sub-theme one: Empowering patients

All healthcare professionals interviewed stated that successful T2D management involved patients ‘owning’ day-to-day self-management tasks, and it was their role of healthcare professionals to facilitate choice and access to appropriate resources. This was underpinned
by the belief that healthcare professionals should ‘empower’ patients to successfully achieve clinically-defined targets:

“I accept now that the diabetes is the person’s diabetes, not my diabetes and my role is very much to support them [patients]”

HCP#9 - P.1; L.40.

“...the end of the day ... I have told you what that my bottom line is. Keeping your blood sugars within a safe range and not leaving yourself open to complications ...”

Healthcare professionals also gauged successful and unsuccessful T2D management by the degree to which an individual patient could act independently, and/or respond to T2D-related needs. It was this capacity for independent self-management that healthcare professionals assessed in encounters with their patients, frequently contrasting this with the perceived failings of paternalistic, directive approaches.

“I think in the old days we used to go in with a checklist – OK, they’ve diabetes and we’d tick off all these things and say ‘I’ve taught them about this’ ... ‘I’ve taught them about this’ and go down the list ticking them all off and when they came back three months later – Oh come on, how come they haven’t got the hang of this, their blood sugar is still in the sky... They’ve not done what they’re suppose to – and it doesn’t work that way. Not if they feel they need to do it for someone else.”

HCP#6 - Page 1; L.46.

“I think for us it [empowerment] just gives us a really good feel of how people want to be supported in managing their illness because essentially if you have a chronic condition you’re the only person living with it 24/7.”

HCP#8 - P.1; L.39.

Therefore, healthcare professionals argued that patients had the ability to manage T2D independently and gauged successful management by the degree patients were perceived to have achieved this. Hence, healthcare professionals found ‘non-compliant’ patients particularly frustrating:
“Although I promote self-management, I don’t particularly like being challenged by patients and I find it intensely frustrating when they won’t comply with what I’m telling them to do, even though theoretically I believe in self-empowerment.”

HCP#10 - P.3; L.3.

Healthcare professionals believed that information provision was a key to patient-related behaviour change, as it provided evidence-based options that facilitated informed patient choice:

“It's giving people the information that we have so that they understand it and then can make a decision themselves as to what they want to do with that information. Now if they understand that information and choose not to, not to act on that information that's fine, because it is their choice, so as long as we've given them the information and they understand it then it's their choice whether they take it up or not, [...]to you know, to take their medication every day or to adjust their insulin and if they just choose not to do it then that is their choice, so I'd never force somebody to do something that they didn't want to.”

HCP#6 - P.4; L.47/ P.5; L.49.

The expectation was that information outlining potential complications and ways to avoid them should be sufficient basis for patients to commit to behaviour change and prioritise clinically-recommended behaviours.

‘I have given you [patient] the information, it's called informed choice, I have explained what the risk and the benefits are, so you tell me what you want to do.’

HCP#7 - P.4; L.15.

Therefore, successful management was portrayed as the capacity of patients to understand health information, and the degree to which this informed their self-management ‘choices’.
“But there are people who, for whatever reason, don’t take on board the information. They’re not engaging, and sometimes it is difficult to find out why they’re not engaging, because ... because they're not engaging, so it's hard to know what we can do for them.”

HCP#6 - P.5; L.49.

It was not always well-informed patients who grasped clinical recommendations that were held up as exemplars of ‘empowered self-management’. These patients were often seen as having unrealistic expectations.

“[S]ome of the terminology I ... I didn’t understand at all because he [patient] would go into the absolute microscopic detail of the human body. [...] I just thought: ‘Golly, I hope there aren't too many characters like that about’. I pointed out it wasn’t the right time for him to be doing that. You know – ‘Gosh this is really interesting, but I can’t really cover it all now’... Yes, I have never come across, before or since, anybody quite as ... strong-willed as that...But it is an issue. And it was all so inappropriate, like he is on a crusade. Yes, completely barking and up the wrong tree...”

HCP#7 - P.8; L.26

Healthcare professionals frequently described patients who struggled to self-manage as having ‘learned’ dependency and expecting paternalistic care.

“People are brought up to believe in a paternalistic model of health care provision, but also people live in a very dependent ... I think in a very... dependent way now in terms of their health and social care. And they feel that if they’re ill it’s someone else’s fault and that the government will sort it out, the NHS or social services, and it absolves them from the responsibility. Which must be, I think, a very convenient coping strategy.”

HCP#10 –Page 3; Line 10.

Overall, healthcare professionals have a view of an ‘ideal type’ of successful patient self-manager – a self-directed person, with expectations which are deemed appropriate, who can ‘own’ their condition.
Healthcare professionals referred to both complicating factors in peoples’ lives and psychological barriers as shaping patients’ capacity:

“Side effects of medicines, maybe they don’t want to take tablets, or a busy life, a newborn blah blah [...]. The bottom line is to keep the diabetes well controlled by adapting it to what they feel they can do – Avoid complications and minimise risk to patients.”

HCP#7 - P.8; L.6.

“Some patients will find it a challenge, they don’t believe they have what it takes to manage a complicated illness like diabetes. Whether it is their confidence, you know, belief in what they can do, or just how they feel about themselves ... a lot of patients like to deny it ... so you have to ground them, give them the choices, so they can at least try ...”

HCP#4 - P4; L.16

A few healthcare professionals described less individualised barriers to empowerment and alluded that differences in the ability of patients to self-manage may relate to age and socio-economic status:

“This is clearly a generalisation but the profile of the group, as I say if you take the population of [Borough], there's about 9,000 diabetics [...] but of that group which should be the whole spectrum of the population, age and gender and whatever, we're dealing with an older population, probably 50 to 70, low socio-economic, so it might be actually the fact that because the group might not have these skills.”

HCP#9 – Page 13; Line #44.

Patients perceived to have paternalistic or high expectations of services were deemed to be demanding and managing unsuccessfully by healthcare professionals. Patients unable to meet clinical targets were seen as wilfully non-compliant, unable to prioritise, or having complicating circumstances which they did not have the necessary skills to overcome. Sometimes, this was associated with age and deprivation. There was a strong connection
made in healthcare professionals’ accounts between individual capacity and the attainment of clinically-recommended behaviours.

Sub-theme two: Empowerment as practise

A clear distinction was made by the healthcare professionals interviewed between a healthcare ethos of ‘empowered self-care’ and other directive ‘paternalistic’ approaches which were seen to have previously informed practise.

“It’s crucial you assign importance to the patient, because if you don’t know where the person’s coming from, what’s happening for them and what they are prepared to do – then you’re a fool to yourself. Because you can write anything in a letter, but the patient goes home and does something completely different.”

HCP #7 - P.8; L.6.

Healthcare professionals also reported changes in their practices as a result of this shift in approach. First, were changes in the armoury of solutions available to address patients’ needs. For example, healthcare professionals noted that changes in health education, technology and pharmacology had enabled their ability to work around factors in patients’ lives.

“[S]ometimes you can tailor things... We have more flexibility... For example, with shift work I will prescribe drugs that will avoid making their sugars go low because we have so much choice now. We have ones now that work with hyper-sensitised body systems, so it works better but it means that they can’t make their blood sugars go too low. So someone who works shifts I will tend to give them that combination, letting them control their diabetes.”

HCP #7 - P.8 ; L.24.

So the whole process of managing had to be, I think, is strongly lead from the individual - but within a supportive structured framework because they can’t do it on their own.’’

HCP#7 - P.1; L.20.
Secondly, empowerment was seen as overcoming the ‘problem’ of healthcare professionals being viewed as the sole source health management:

“[Y]ou only see a healthcare professional for about two to, maybe at the most, 10% of your time every year, so the rest of the time you're on your own, so if you can self-manage your diabetes, you can adjust your medication [...] to reduce your risk of complications. If you're always relying on a healthcare professional to manage it for you, it's not going to be managed as often.”

HCP#6 - P.2; L.4.

Empowerment was portrayed as enabling T2D management by centring care around the individual, rather than telling patients what to do.

“I guess because you don't feel quite so paternalistic, because you're not telling people what to do all the time, you're giving them choices and you're helping them to do it themselves, so it is a different way of working.”

HCP #6 - P.7; L.13.

A few healthcare professional participants argued that the process of jettisoning paternalism should be graduated. These participants stated it was necessary to work with patients’ expectations of directive care as a stop-gap to encouraging greater self-directed care:

“Some people want me to take the paternal - or maternalistic in my case - role towards their care and direct them. That’s fine you can gradually let them take charge.”

HCP#7 - P.4; L.26.

Conversely, directive, paternalistic approaches were portrayed by some as barriers to effective patient self-management in themselves.

“You are not helping them [patient] if you don’t get out of them what they feel can and can’t do. You are just telling them what to do. Then, hoping they do it, and next time they are in your clinic, if there is a next time, they just feel like they haven’t done what they are supposed to.”

HCP#6 – P2; L.9.
Empowerment offered healthcare professionals a theoretical and practice-based foundation which constituted a shift in practise overly-directive patient care approaches were obsolete (these paternalistic approaches were reported by some as a barrier to empowered T2D-management). Facilitating choice and finding ways to work around patient circumstances enabled and ‘empowered’ patients to successfully self-manage by centring care around patients’ needs. Some healthcare professionals thought this shift should be graduated, as paternalism enabled eventual empowerment. Successful management was measured largely by the degree to which the patient was seen to be autonomously following clinically-informed recommendations.

Sub-theme three: Empowerment as healthcare delivery

We have seen that healthcare professionals sought to work around patient concerns using the empowerment approach. Healthcare professionals discussed in equal measure the need to manage T2D within the confines of the healthcare system.

First, it was argued that targeting care around the patient was also seen as responsive to need and thus cost-effective:

‘‘I think that unless we ask the opinions of the people who are going to use this service there is absolutely no way of knowing that we can meet their needs.’’

HCP#8 - P.1; L.4.

It was seen that improving the quality of the patient experience (through incorporating their concerns) improved the reported quality of services provided.
“They [patients] make sure that we are keeping up standards and developing services that are appropriate for our community... they have choices about going elsewhere. So I think they drive quality from many different levels.”

HCP#7 - P.1; L.32.

It was further argued that working closely with patients to identify need intrinsically changed the quality of health services provided:

“[G]etting opinions and also getting service user experiences and allowing them to shape services which I think is absolutely paramount in a chronic illness like diabetes. We are starting with the patients as benefactors, instead of seeing them as reaping the benefits”

HCP#8 - P.1; L.4.

It was also argued that there were finite resources available for health and that patients needed to pick up ‘‘some of the slack’’ in healthcare provision (HCP#1).

“The NHS will always have a finite amount of resource to go round [...] If patients can pick up some of the slack, and self-manage their diabetes, there is less NHS has got to cover ...”

HCP#1: P.2; L. 33

Empowerment as applied to health delivery was seen by healthcare professionals to centre on consulting with patients to drive cost-effectiveness through targeting services, improve quality of care and allow control of finite resources.

There were concerns with tokenism, where listening to patient concerns and tailoring available resources to individuals were seen as a lip-service.
“At the end of the day the PCT as far as I’m concerned there is a rhetorical commitment to it and they’ll do as little as they can to actually make it a reality.”

HCP#4 - P.1; L.50

Many saw empowerment as a way of bending the rules to achieve the best outcomes for their patients.

“I am changing things from the inside, I am not a policy animal. I quite honestly find that everything is over-regulated anyway and I think that we have to jump through hoops.”

HCP#3 - P.3; L.42.

“It comes down to bending policy or seeing a third way or you know, being creative with the policies, you know. A case of ‘if it doesn’t say you can’t do it...’ So taking power.”

HCP#9 - P.3; L.4.

A few healthcare professionals also reported inherent contradictions in a health system driven by clinical targets, and the process of empowering an individual to self-manage.

“[Q]uite often people [...] who don’t wish to comply with say, for instance, our QOF targets which we’re trying to meet. They are able to become expert patients and then justify to me why they don’t wish to comply. So it really gives them [patients] the ammunition to say I am well informed, I’m an expert, and I don’t want to take blood pressure pills because they make me feel ill [...] And I think you cannot ignore the dilemma that health care professionals are put in [...] and the two don’t match up.”

HCP#10 - P.8; L.11.

Sub-theme four: Empowerment as social change

In following the ethos of empowerment, all healthcare professional participants argued that self-management was a necessity, as given epidemiological change and the growth of chronic illnesses the patient role needed to change from ‘passive’ to self-directed.
“[T]he whole process of managing had to be, I think, strongly lead from the individual - but within a supportive structured framework because they can’t do it on their own.’’

HCP#7 - P.1; L.16.

A few healthcare professionals added to this by arguing that, when working in a deprived area it was important to consider features of the population as well as issues of social justice.

‘‘. . .[I]f you don’t empower the users of services, and the community in its wider context, then you could argue that those services are poorer and not so relevant. But particularly in health, given that we have a statutory responsibility to involve patients in the last couple of years, then I think it’s an area that needs developing further, and really to a certain extent, our democracy. If we live in a democratic society then our services should be within that spectrum.’’

HCP#9 - P.4; L.44.

By acknowledging socio-contextual issues – particularly the emphasis on shifts at the population level in terms of chronic illness - healthcare professionals saw larger social changes informing the challenges they faced in their day-to-day encounters with patients.

For example, where emphasis was placed on the shift towards chronic illness management at the population (social change) level there was an emphasis on managing scarce resources at the delivery level, there was a perceived need to practise empowered self-management techniques (as an approach) to combat learned dependency (thus empowering the patient).

This was seen as a way of improving service quality and targeting resources to produce behaviour change.

“You can’t leave them with no hope, but you can’t be looking over their shoulder either. So we give them choice based on what we know works, and what is best practice for the diabetic population [...] There has to be some commitment from the patient to make it work, otherwise there is no point in us being here. It can be small, not eating crisps and sweets and alcohol, taking a walk … You know… We need to see that commitment, so we can work together.”

HCP#9 - P.4; L.24.
Healthcare professionals who discussed empowerment as an issue of social justice (managing social change) saw practising as an appropriate use of resources and tailoring clinical solutions as an issue of equity and equality (in the healthcare delivery) which enabled targeting and empowerment of the most needy (empowering patients).

“Do you think using resources inappropriately is equitable? When it’s wasteful to give resources to people who don’t need them, or can’t use them? So for us it is about making decisions over aspect of services that can have an impact. It has to be seen to be transparent, and not just be education, again.”

HCP#7 - P.1; L.48.

In short, healthcare participants saw empowerment as a way of managing scarce resources in light of epidemiological change, and/or relating to issues of social justice and democratic renewal. This shaped their views of how to empower patients.

**Overview of healthcare professionals perceptions, understanding and experiences of managing T2D**

Healthcare professionals described listening to patients concerns as enabling the tailoring of information at the patient level. Information provision was seen as a key element of managing T2D, as it facilitated ‘informed choices’ and better self-management in patients. Although some saw the incorporation of patient views in T2D-management at the health service level as potentially tokenistic, and a barrier to successful management.

‘Unempowerable’ patients were seen as wilfully ignoring clinical recommendations and not prioritising T2D in their lives (in spite of the information and evidence). Some healthcare
professionals implicated socio-contextual factors, such as poverty and old age, as acting as a barrier to empowered self-management. Healthcare professionals assessed successful management according to ability to choose, practice and attain recommended clinical outcomes. Paternalistic approaches were seen as contributing a learned dependency, whereas empowerment was seen as facilitating self-management, choice and ownership of T2D by the patient. Some healthcare professionals also described paternalistic approaches as an enabling adjunct to empowered self-management. Others perceived inherent contradictions in attempting to marry clinical aims with the needs and concerns of patients. One key component of successful T2D-management reported was the management of scarce resources. At the level of socio-context, successful T2D management was seen to be responsive to epidemiological change and contributing to democratic renewal.  

5.3. Contrasting patients’ and healthcare professionals’ perceptions, understanding and experiences of managing T2D

5.3.1. Congruence

There was congruence in reports of patient-related barriers to T2D-management, between patients’ accounts of the uncertainty and apprehension when managing T2D e.g. how to respond to symptoms - and healthcare professionals’ accounts of patients lacking understanding of how to manage T2D. The stratified manner in which T2D was managed by patient participants, and ways in which information was sought and applied by patients, suggested that patients were: 1) often not ready to digest the information they have been

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2 This aspect of the study relating to how healthcare professionals apply empowerment in practice has been published in greater detail as: Newton, P, Scambler, S & Asimakopoulou (2011) Marrying contradictions: Healthcare professionals perceptions of empowerment in the care of people with Type 2 Diabetes. Patient Education and Counseling , 85, 3, e326–e329. A copy of the paper can be found in Appendix 3.2.
given, e.g. the newly-diagnosed who manage through routinisation; or 2) healthcare professionals’ styles of healthcare delivery did not reflect patient expectations, e.g. those who feel burdened by care expect more directive care.

In exploring patient-related enablers to self-management, patient participants often looked for ‘pay-offs’ to self-management behaviour which reinforced these efforts, e.g. improvements in health status. These pay-offs tally with healthcare professionals’ tendency to measure patients’ progress against recommended clinical targets, and equating personal control of T2D with empowerment. The finding that some patient participants looked to healthcare professional encounters to gauge their efforts in self-managing suggests that this congruence also occurs productively in clinical encounters. This congruence can reinforce the idea of self-directed care as a ‘choice’, and bracket out the barriers to self-management that other patients reported e.g. perceived lack of professional support. Emphasis on ‘informed patient-choice’ as determining health outcomes may lead to scenarios where patients see lack of progress, or increased severity an individual failing.

Another pronounced congruence in successfully managing T2D occurred at the systemic-level - The perceived need to minimise patient reliance on health services, and to manage scarce resources was reported by both groups. However, the majority of patients diverged with healthcare professionals on the reasons why minimal use of healthcare professionals was considered an important indicator of successful self-management e.g. minimal use of services could be perceived as T2D being kept at bay - whereas, healthcare professionals’ asserted that the reduction of health service utilisation demonstrated patient expertise in managing T2D. The closest fit to this development of ‘expertise’ assertion in patient participants’ styles of self-management were those participants who co-managed T2D with healthcare
professionals. These participants reported acquiring expertise either to challenge the clinical options that healthcare professionals’ gave, or to overcome lack of continuity of care. This suggests that many patient participants attained expertise in T2D and sought partnership arrangements with healthcare professionals, in spite of the empowerment, rather than as a result of it.

Although there is a superficial congruence in these accounts, there were differences in the descriptions of motives and evaluations of un/successful management. Patients’ accounts do concur with healthcare professionals’ accounts that minimal use of healthcare services occurs with experience and over time. Also at the socio-contextual level there is agreement between some healthcare professionals and patient participants that socio-contextual factors, such as poverty and advanced age, can act as a barrier to self-management.

5.3.2. Divergence

In healthcare professional accounts of un/successful T2D-management was gauged as follows:

1) At the patient level, the degree to which self-directed effort contributed to attaining T2D clinically recommended targets;
2) At the healthcare professional-level, the degree to which practising in an empowering enabled 1 (above) and 3 & 4 (below) and reduced paternalism in practices;
3) At the healthcare system-level the degree to which empowered T2D management allowed for management of finite health resources and drove quality of services; and
4) At the socio-contextual-level, the degree to which empowerment addressed concerns relating to epidemiological change and issues of social justice.
Patient participants’ accounts of gauging un/successful management and the barriers and enablers they experienced reflected these various levels but often in a stratified manner and with different effects. Un/successful management was gauged by patient participants as follows:

1) At the T2D-related level, according to experiences and perceptions of deterioration and health gains;

2) At the patient-level, through the degree to which self-management posed various barriers and/or was disruptive to day-to-day routines, as well as - in some cases - comparison with other patients;

3) At the healthcare professional-level, un/successful management was seen through the lens of different types of support that were needed from healthcare professionals to self-manage (either seen as minimal or currently insufficient);

4) At the socio-contextual-level, patients experienced different barriers and enablers and brought varied resources which shaped their self-management styles (and their gauges of self-management).

At the patient-level, healthcare professional gauges of self-management centre on measuring self-directed activity against attainment clinical targets. This is in stark contrast to patient participants who sought minimal disruption to routine behaviour, independence and to live like the rest of the population. Patient participants gauged self-management as successful when it had little or no impact on day-to-day routines, and where existing divisions of labour were preserved (particularly when self-managing T2D through routinisation, through delegation or keeping T2D at bay) or allow them freedoms from T2D routine. A few patient
participants self-managed to maintain personal control, whilst others saw themselves as burdened and requiring more professional support. As such, patient participants had different information-seeking styles and reported various divisions of labour within their households and sought to have different degrees of personal control over managing T2D. This suggests that the empowerment approach, when applied by healthcare professionals, may overstretch the focus on *individual capacity* to self-manage and achieve clinical targets independently. In most instances the healthcare professional stance, is diametrically opposite to some patients’ actual styles self-management and the way patients gauge successful T2D-management e.g. managing T2D as a burden. This divergence explains why healthcare professionals saw patients’ expectations, particularly those they deemed as having learned dependency or to be too ‘pushy’, as being inappropriate and a barrier to empowerment.

Healthcare professionals’ accounts of successful management saw un/successful management at the *healthcare professional and health service level* as an antidote to paternalistic approaches to healthcare provision. Empowerment, when applied to service delivery, was seen to offer ways to manage finite health resources whilst improving services through incorporating patient perspectives. This incorporation of patient views was prone to being selective - according to whether patient expectations were deemed to be appropriate. The majority of patient participants agreed that there were finite resources available for health, adjusted their use of health services and gauged minimal use of services as successful management. What was significant was that only those within the co-managed and autonomous styles of self-management, sought information to assess clinical options and to challenge healthcare professionals. These patient participants reported being able to leverage their preferred outcomes whilst minimising contact with services – rather than reduced contact being seen as successful per se. Managing healthcare professionals and services
became part of successful self-management for these patient participants. The gatekeeper role healthcare professionals adopted and the poor quality of services were seen by these patient participants as a barrier to successful self-management. These participants also reported being able to secure the resources they needed to self-manage, and some had brought a socio-economic advantage with them which was shown to enable more strategic self-management and neutralise many barriers to self-management.

Given the above, although empowerment was seen to offer a way of managing finite resources in response to epidemiological change at the socio-contextual level, it can be argued that some patient participants were better able to secure health resources. The notion that empowerment can address social justice issues is divergent from the patterns of access to services described by patient participants in this study. First, although some patient participants reported using services minimally as a gauge of successful T2D management within this group, some patients developed styles of information-seeking that gave them greater leverage in their healthcare encounters. The converse was true with patients managing severe forms of T2D as a burden, having low incomes, increased T2D severity and when seeking help are labelled as having learned dependency by healthcare professionals. Therefore, when applied in healthcare, empowerment may actually complicate and exacerbate issues relating to equitable use of resources and democratic renewal by focussing on individual capacity, and bracketing out how the stratified nature of patients’ social contexts shapes self-management.
5.3.3. Healthcare professional and patient-specific concerns

Patient participants’ accounts of T2D self-management provided numerous examples of how T2D-related severity created barriers to self-management. Healthcare professionals’ accounts of diagnosis and adaption saw the newly diagnosed as having specific needs, but severe forms of T2D were virtually omitted. Accounts from patient participants who lived with increased T2D severity suggested that greater intervention and support from healthcare professionals was required to manage independently. There was some willingness in healthcare professionals to use directive, empowerment approaches as a platform for ‘empowerment’. This suggests that the wholesale rejection of ‘paternalistic’ approaches may be inappropriate as some patients do seek, and may require, additional support from healthcare professionals to independently self-manage.

Healthcare professionals’ applications of empowerment tended to individualise how T2D should be successfully managed at the patient-level. Reports of social support as an enabler to self-management in patients’ accounts were omitted from healthcare professionals’ accounts. Many patient participants reported benefitting from co-carers attending healthcare encounters, but patients’ home circumstances were often seen as barriers to self-management. Rather, information provision pertaining to clinically recommended behaviours (as described by healthcare professional accounts) was seen as a toolkit for all circumstances. As such, empowerment sought individual choice, personal capacity and prioritisation of T2D-related behaviours, which bracketed out how patients’ lived in a network of relationships in their social contexts, and were often not alone in ‘living with, and managing T2D’.
Chapter Six – Discussion

Chapter headings:

Introduction

6.1. What are patients’ and healthcare professionals’ perceptions, understanding and experiences of successful and unsuccessful (un/successful) T2D management?

6.2. What barriers and enablers do patients and healthcare professionals perceive, understand and experience in relation to managing T2D on a day-to-day basis?

6.3. What similarities and differences emerge in patients’ and professionals’ perceptions, understanding and experiences of managing T2D on a day-to-day basis?

6.4. Methodological strengths and limitations of the present study

6.5. Areas for further research

6.6. Practical applications of the work
**Introduction**

This chapter synthesizes the findings of the present research by placing it in the context of the existing patient, healthcare professional and ‘contrast’ research pertaining to perceptions, understanding and experiences of managing T2D. The findings of the present work support some, but contradict other findings of previous studies looking at both patients’ and healthcare professionals’ perceptions, understanding and experiences of managing T2D. The present work also offers unique insights by identifying gauges of successful and unsuccessful management as well as barriers and enablers to T2D management for both groups. Moreover, further insights emerge from comparing and contrasting patients’ and healthcare professionals’ perceptions, understanding and experiences of managing T2D.

The chapter begins by answering the first research question relating to patients’ and healthcare professionals’ understanding of what constitutes successful and unsuccessful T2D management (section 6.1.). This section also highlights how the present research contributed to, and built upon, current knowledge. The section concludes that although both patients and healthcare professionals engaged with T2D management on similar levels, their evaluative contexts and criteria for un/successful management were largely different.

The chapter goes on to discuss the barriers and enablers both groups reported throughout the research (in section 6.2), and how they contribute to, and enhance existing knowledge. The barriers and enablers reported by both groups were realised through their day-to-day management. Hence, patient barriers and enablers were largely informed by factors in their immediate social contexts and in accordance with their gauges of un/successful self-management they developed. Healthcare professional-related barriers and enablers were
informed by how their day-to-day practice of empowerment which was their main gauge of un/successful self-management.

The next section of the chapter discusses how results that emerged from comparing and contrasting patients’ and healthcare professionals' perceptions, understanding and experiences in this study (section 6.3.). The section highlights how the present study relates to, builds upon, and brings new insights not found in, previous studies. The section highlights that the different evaluative criteria that patients and healthcare professionals use can both diverge and converge in ways that facilitate or constrain the management of T2D.

The chapter then outlines the methodological strengths and limitations of the present research (section 6.4.) in terms of transferability (how generalisable the findings are) and credibility (whether the data was an accurate reflection of the perceptions of the participants’ views and experiences). The final section (6.5.) suggests potential areas for further research.
6.1. What are patients’ and healthcare professionals’ perceptions, understanding and experiences of successful and unsuccessful (un/successful) T2D management?

The present study found that patients and healthcare professionals frequently gauged un/successful management in different ways. It was found that both groups of participants mediated, and then struck a balance between a variety of issues that emerged from managing T2D on a day-to-day basis. Both sets of participants derived evaluation and assessment criteria for gauging T2D management success using a process of mediating between their personal concerns and factors in their social contexts. Patients tended to evaluate the impact of managing T2D by its ramifications for day-to-day life. Whereas healthcare professional gauges rested on the patient’s ability to internalise clinically recommended behaviours, patients independently managing T2D, and wider healthcare-related benefits perceived to be associated with this. Patients’ gauges of un/successful management were found to vary across the course of the illness, and to be stratified according to severity of the condition and resources in their social contexts.

Hunt and Arar (2001), Cohen et al. (1994), Zoffman et al. (2008) and Tang et al. (2006), amongst others, have all previously found healthcare professionals and patients varied in terms of the evaluative context they used as for measuring the success of T2D management. These aforementioned studies, argued that the patient’s focus was largely on the social (“life-orientated”) domain of illness whereas healthcare professionals’ focus was on clinical (“disease-orientated”) concerns (Zoffman et al., 2008). The present study, similarly found that patients’ and healthcare professionals accounts varied in the evaluative contexts they used. The present study, however, added to existing research by finding that:
1) Patients’ gauges of un/successful management developed across the course of the condition i.e. throughout the diagnosis, adaption and management stages. 

2) Gauges of un/successful management varied within the patient group e.g. routes to diagnosis and different styles of self-management resulted in different criteria being employed to measure success.

3) Some patient participants understood the clinical evaluative context of healthcare professionals - and its criteria for un/successful management - and could employ this understanding to maximise how they harnessed and used health resources;

4) Although empowerment was the main gauge of un/successful management used by healthcare professionals, some argued a degree of paternalism is sometimes required to encourage patients to self-manage; and

5) Healthcare professionals gauged T2D management using the patient, practise, health delivery and wider socio-contextual levels, and used the empowerment to marry together the disparate aims of T2D management emerging across multiple levels;

6) Healthcare professionals sometimes found that their clinical gauges of un/successful management were contradictory to the aim of empowering the patient.

In demonstrating the first point, relating to patients’ gauges of un/successful management changing over time we can see that in the present study, patient participants’ accounts of diagnosis, as a personal experience, were shaped by route to diagnosis. This reflects the work of Hiscock et al. (2001); Peel et al. (2004a) and Parry et al. (2004). In line with these authors, the present study found that diagnosis was considered successfully-managed by patients if it was managed well by healthcare professionals. This included instances where patients felt they received appropriate information about managing symptoms, and in the case of screening – explanations of test results by healthcare professionals provided ‘proof’ to the patient of changes in their bodies. This supports the work of Polonsky et al (2010) suggesting
that diagnosis should be delivered in a fashion to allay distress, and the work of Peel et al. (2004a) that detailed information should provided at the time of diagnosis. The findings of the present study suggest that patients wish to gain a clear understanding of the physical manifestations, particularly identifying the symptoms of T2D, and how to manage them, immediately post-diagnosis. Instances of poor delivery of diagnosis and misdiagnosis were reported as examples of poor management of diagnosis. This suggests that healthcare professionals and health service provision are an important gauge of un/successful diagnosis for patients.

The present work uniquely captured how symptoms were managed (by patients) prior to formal diagnosis. Patient participants equated successful symptom management prior to formal diagnosis with many being able to identify symptoms and respond by self-referring, with some even self-diagnosing. Patient participants related unsuccessful management of symptoms as being able to explain away or ignore symptoms, having more important priorities. Whereas, the work of Peel et al (2004a) and Eborall et al (2007) with the newly diagnosed and screening patients, suggests that patients are willing and capable of absorbing T2D information at the time of diagnosis. The present study found that different symptom status at the time of diagnosis and route to diagnosis conferred different practical experience of managing symptoms to patient participants prior to diagnosis. This will need to be reflected in healthcare professionals’ approaches to diagnosis. Also, identifying and managing symptoms was a key source of uncertainty for patients following diagnosis, and also acted as a barrier to adaption, and thus establishing routinised self-management.

Similar to the findings of Moser et al (2008) patient participants were found to perceive adaption as a recursive process. The present work found that this was because clinically-recommended behaviours were applied and accommodated by patients adjusting factors and circumstances in their immediate social contexts. This meant adaption was found to be
necessary as the illness progressed or circumstances changed. Un/successful management was assessed by patients according to the ramifications T2D had for their day-to-day lives, i.e. their social context.

Previous research on the ways people adapt to living with T2D has tended to focus upon narrative approaches concerned with disruption and reconstitution of understanding post-diagnosis (Hornstein et al; 2003; Rajaram, 1997). Narrative approaches focus on personal, phenomenological experiences of rebuilding life post-diagnosis. Other studies have concentrated on factors that impact on the degree to which a person adapting to living with T2D can follow clinically recommended behaviours (e.g. Moser et al., 2008). The present study, having looked at the evaluative criteria patients developed similar narrative approaches (Bury, 1982; Williams, 1984), found that people adjust the personal, material and socio-contextual resources to ‘fit’ T2D behaviours into their lives. The present research also found that these factors were patterned by the social context people live in, and that these social contexts that have varied resources and circumstances. As such, patients’ gauges for un/successful adaptive effort in the present study reflect the impact that living with T2D has on their social contexts (and vice versa), rather than looking at the effects of ‘competing priorities’ in their social contexts or ‘narrative disruptions’ in singularity.

The balance that patients struck in applying T2D-related behaviours within their lives eventually led to some kind of routinisation, and later to the development of a style of self-management. The balances struck were an amalgam shaped by the severity of their T2D, perceptions of the care they received, circumstances and resources in their socio-contexts (and hence, the personal constraints and facilitators they perceived, understood and experienced). If we look at the main typologies that have been developed in the literature we can see that the majority of studies usually focus on a few, limited factors which shape patients’ perceptions, understanding and experiences:
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<td>Who took responsibility for care</td>
<td>Acceptance of future consequences; and Acceptance of ‘diabetic identity’</td>
<td>Self-care value; and Who took responsibility for care</td>
<td>Attaining motive for self-management; Divisions of responsibility for care; Use of health information; T2D and socio-demographic characteristics; and Barriers and enablers that were commensurate to gauges of self-management Social comparisons Use of health services</td>
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Table 8: Previous typologies of patient self-management and gauges of un/successful management and typology of current study.
As we can see, gauges of the relative success of self-management in the existing literature vary according to the degree to which purposeful action is: a) superseded by competing priorities in day-to-day life (e.g. Kelleher, 1998); b) whether the person accepted the future consequences of T2D (e.g. Ockleford et al, 2007; Collins et al., 2009; Hunt et al, 2007); and/or c) the degree to which someone else takes charge of care (e.g. Hunt et al., 2007; Collins et al., 2009).

The present study, although finding similar factors in patients’ accounts of self-management, did not assume that patients, above all, sought to individually and purposefully manage their illness. Rather, the assumption was that patients mediated between socio-contextual and their personal concerns to fashion a modus operandi for self-management. Hence, whereas previous studies have developed typologies based on the degree to which patients could maintain the purposeful individual intention to self-manage, or could focus on the future consequences of T2D in light of competing concerns, the present study demonstrated that patients developed different motives for self-management which were fashioned in light of their the stage of their illness, their circumstances, their experiences of applying T2D-related behaviours within their day-to-day lives, as well as preceding and emerging factors in their social contexts.

The different evaluative contexts and criteria used by patients and healthcare professionals resonate with the work of Hunt and Arar (2001). However, Hunt and Arar (2001) homogenised their sample to only include people living on a low income. The present study, using a sample with varied incomes, found that patients on higher incomes with years of experience managing T2D had skills, social contexts and access to resources which facilitated the practice of self-directed care. Figaro et al. (2009) found patients’ expectations of health outcomes when self-managing were lower in those of a lower socio-economic status.
Similarly, the present study found that the resources patients have available to realise and act on their motives are concomitant with factors in their social contexts.

Intrinsic to this, some patient participants were able to access and maximise their use of healthcare resources as these participants were able to reflect and often understand healthcare professionals’ evaluative criteria and had experiences and resources which facilitated successful self-directed T2D management styles. Equally, older people, on lower incomes with severe forms of T2D often sought additional help from healthcare professionals to be able to self-manage and gauged successful T2D management in these terms. Patients also saw minimal use of (and need for) services as a gauge of successful management. Hence, similar to work such as Lawton et al.’s (2008) study, the present work found that patients used encounters with healthcare professionals and services to gauge their self-management efforts, and also gauge the seriousness of their illness by the types of services they receive. The present study had similar findings but also found that patients also used these encounters with healthcare services to secure support, advice and treatment, i.e. health resources. However, a few patient participants used their ability to manage healthcare professional encounters and harness healthcare resources as a gauge of successful T2D self-management. It was found that the latter capacity was facilitated by preceding socio-demographic factors (such as income and education) and came with time.

Healthcare professionals’ gauges of un/successful T2D management centred on patients’ perceived willingness or ‘capacity’ to adopt clinically-recommended behaviours and attain the related targets, this was referred to as patient empowerment. This echoes the findings of Asimakopoulou et al.(2011) and Scambler et al . (2012), however the present study outlines how wider levels of T2D management are shaped by adoption of the empowerment approach. This central gauge – the process of empowering the patient to self-manage - was the lynchpin of successful management. Empowered, self-directed patient care was seen to lead to new
ways for healthcare professionals to practise, whilst negating the damaging effects of paternalism. However, the use of paternalism by healthcare professionals in the present study did occur in degrees, and in order to promote self-management. Wens et al. (2005) found that healthcare professionals use paternalistic approaches when frustrated with patients’ non-compliance. This is contrary to the present study where healthcare professionals reported plugging shortfalls in the empowerment approach using paternalism. In some instances, healthcare professionals established a healthy clinical baseline for the patient through a directive approach, and then weaned the patient towards self-management. Adolfsson et al. (2004) has postulated that as healthcare professionals experience difficulties as they switch from the role of expert in acute care settings towards ‘facilitators’ supporting long term T2D management by patients. However in the present work, as noted, when exploring healthcare professionals’ accounts of diagnosis and adaption there was a strong future orientation – in contrast to patient focus on more immediate issues. This suggests that healthcare professional gauges of the acute aspects of diagnosis (e.g. the addressing of symptom identification and patient uncertainties) is being replaced by an emphasis on gauging deficits in patient behaviour in light of the chronic nature of T2D and on facilitating long-term self-management.

Empowerment was also perceived by healthcare professionals to be gauged by whether or not it contributed to making healthcare delivery more responsive and healthcare services more effective. Luftey (2005) has asserted that healthcare organisation supports or inhibits the practise of empowerment. However, healthcare professionals in the present study argued that it was possible to improve the responsiveness of healthcare services by listening to patient need, i.e. supportive healthcare environments were possible when services are designed around the needs of patients. One issue with this approach is that patient need is frequently filtered through healthcare professionals asserting the notion that successful self-management is the attainment of clinical targets. This gauge would appear to be almost exclusively shaped
by healthcare professionals and people living with T2D who use services as a resource to attain clinical targets. Equally, improving healthcare delivery through empowerment of the patient meant that healthcare professionals could successfully manage finite health resources whilst addressing wider concerns relating to epidemiological and social change. This supports the work of Scambler et al. (2012) that empowerment approaches conferred greater resource control to healthcare professionals. If empowerment does allow for health resources to be managed in a patient-led fashion whilst addressing wider social and epidemiological changes, then patient need in this scenario is again largely shaped by healthcare professionals’ perceptions, understanding and experiences.

6.2. **What barriers and enablers do patients and healthcare professionals perceive, understand and experience in relation to managing T2D on a day-to-day basis?**

Patient participants realised barriers and enablers to managing T2D through applying T2D-related behaviours in the context of their day-to-day lives. The barriers and enablers to T2D management which patients experienced emerged from the application of T2D within their day-to-day social contexts. Previous studies have tended to list barriers and enablers to T2D management in terms of: 1) how patients managed T2D within competing priorities (e.g. Hiscock et al., 2001) or 2) of impracticality of the task in daily life (e.g. Hayes et al., 2006). Other studies have taken a more nuanced approach and look at how 3) meeting T2D-related behaviours is initially experienced as restrictive or frightening, but later re-evaluated as enabling when there is seen to be a ‘pay-off’ to self-managing (e.g. Morris et al., 2005; Casey et al. 2010). The present study found that these three approaches to defining barriers and enablers to be interrelated, and each approach described a part of a single process. Patients
mediated between their concerns and assessed the practicability of clinically recommended behaviours within their day-to-day lives (e.g. a person changes their diet and begins an exercise regime). Where a ‘pay-off’ was achieved this lead to the benefits of the practice being understood which reinforced the behaviour, and the behaviour was sometimes reframed. This was because patient participants felt they now had evidence of their ability to respond to T2D, e.g. changes in diet lead to health improvements for the patient, and their whole family’s health. These ‘pay-offs are also described in other studies such as Morris et al. 2005. Conversely, self-management activity could be seen as impractical in relation to other concerns or was felt to be wasted effort (e.g. exercise is found to be time-consuming, painful and disruptive to the routines in the household). In this case, the factors engendered by carrying out the activity have no perceivable ‘pay-off’ or create uncertainty. Equally, the physical burden of managing T2D, and disruption to routine activity in day-to-day life engender opportunity costs and/or add to patients’ personal concerns. Hence, the activity is seen as burdensome, and is experienced as a barrier. However, this study also found that routinisation, divisions of labour within the household, and socio-contextual factors patients brought to self-management, could ‘neutralise’ the effect of some reported barriers and enablers. Therefore, these findings not only synthesise existing work on barriers and enablers to T2D management, but also explain why specific groups consistently experience similar barriers and enablers to self-management. As barriers, enablers and neutralisers are arrived at by mediating between personal concerns and socio-contextual factors, they tend to be realised in a fashion commensurate to the illness trajectory, and to accumulate on the pathways of least resistance within existing social strata.

Previous studies, such as Peel et al. (2004a), Hiscock et al. (2001) and Lawton et al. (2005), have all identified different routes to diagnosis. Peel et al (2004a) and Lawton et al. (2005a) have shown that routes to diagnosis inform patients’ responses to diagnosis by shaping their
information or health service-related needs at this time (respectively). The present work similarly explored how routes to diagnosis shaped barriers and enablers that patients’ experienced. First, it was found that some barriers and enablers were specific to diagnosis routes. One enabler-specific to route to diagnosis found on the screening route was that results of tests often provided certainty to patients by demonstrating to them that T2D had occurred within their bodies, despite the patient often having no symptoms. Routes to diagnosis were found to have route-specific barriers, a finding unique to the current study. These barriers were: 1) reports of difficulties identifying T2D manifestations where diagnosis occurred as result of co-morbidity or dual diagnosis, and 2) loss of capacity to respond to symptoms in the hospitalisation route. This example also highlights how the present study added to this literature by identifying an additional route to diagnosis, the route of ‘dual-diagnosis and diagnosis as a result of managing a preceding co-morbidity’. The latter findings suggest that patients on some routes to diagnosis have specific information and mental-health needs at the time of diagnosis.

Secondly, the present work also added to Lawton et al.’s (2005a), Elstad et al.’s (2008) and Troughton et al.’s (2008) findings that patients experience periods of uncertainty about how to manage T2D following diagnosis, and that this acts as a barrier to responding to diagnosis. Lawton et al. (2005a) found that newly-diagnosed patients sought certainty through accessing different kinds of health services. The present study found, like Elstad et al. (2008) that much of this uncertainty stemmed from patients being unsure about how to identify and respond to symptoms. Equally, the present study additionally found that diagnosis often clarified and addressed the uncertainties patients experienced. This enabled patient understanding of the physical aspects of T2D, thus some patients’ reports of diagnosis were more positive and described how diagnosis acted as a spur to respond to the condition (similar to Peel et al., 2004a).
Thus, one of the key aims of diagnosis should be to address and clarify patient uncertainty. Although the barriers to responding to T2D diagnosis reported so far relate largely to barriers in patient understanding, they do lend weight to the argument that healthcare professionals have a crucial part to play in T2D diagnosis. First, some patients in the present study, as in other studies (e.g. Alazria, 2007; Pooley, 2001), reported that a lack of continuity of care or poor quality care held back their efforts to self-manage T2D following diagnosis. Secondly, reassurance, proof of T2D and appropriately targeted health information can address the uncertainty that many patients experience and facilitate understanding of how they can respond to the condition (Polonsky et al., 2010; Peel et al., 2004a; Eborall et al., 2007). This suggests that the types of uncertainty that patient participants have reported throughout the present study – symptom, response, information and co-management uncertainty - highlight key areas where the barrier of uncertainty emerges. These types of uncertainty can be monitored and addressed to foster the more positive aspects of diagnosis, e.g. technical proof, and certainty about what is causing the physical manifestations of T2D enables understanding of how symptoms can be managed (as has been described above).

One unique aspect of the present study is that it investigated patient participants’ accounts of the events that led to diagnosis in order to identify barriers and enablers patients experienced in attaining a T2D diagnosis. The seemingly benign nature of symptoms reported by patient participants, in most cases, meant that symptoms were easily explained away which delayed self-referral. Similarly, it was found that patient participants also delayed self-referral out of fear and anxiety, or by mistakenly conflating symptoms with existing long-term conditions. These instances of delayed self-referral suggest a need to heighten awareness of early T2D symptoms at the public health level. In contrast, access to diagnostic equipment and, to a lesser degree, previous experience of living with T2D within the family enabled self-referral,
self-diagnosis by patient participants and subsequent formal diagnosis. Given patients, accounts of T2D symptoms being very difficult to identify, the area of promoting self-referral for T2D by encouraging ‘lay’ monitoring of T2D appears to offer a solution. Increasing the accessibility and use of diagnostic equipment and encouraging self-diagnosis poses interesting dilemmas for health services seeking to empower their patient populations. It also highlights that the option of a person being ‘empowered’ to self-manage T2D is only available once verifiably in ‘ill’ health. Thus, patients may not only be unfamiliar or intimidated by having to manage the condition, but by the level of self-directed health management expected by healthcare professionals.

The present study found that during the diagnosis phase of T2D-management, the healthcare professional participants in this study tended to see diagnosis as a point for activating self-management. Hence, barriers and enablers to successful management of diagnosis were equated with patients’ willingness, and sometimes ability, to prioritise the clinically recommended behaviours of T2D self-management to prevent the consequences of T2D. This notion of de-prioritisation and willful denial of T2D diagnosis was not evident in the patient participant sample in the present study. The present study also concurred with Peel et al. (2004) that the orthodox approach in much of the T2D diagnosis literature - that of T2D diagnosis being a ‘shock’ to patients that created denial of diagnosis - is not a prevalent response. Rather, the findings of the present study found that experiences of diabetes were characterised by uncertainty about how to respond to T2D diagnosis, in particular how to reduce physical manifestations, such as high blood sugar.

Healthcare professionals tended to view adaption as an extension of diagnosis, a brief stepping stone before self-management was established. Healthcare professionals gauged un/successful self-management by patients’ abilities to prioritise and choose clinically
recommended behaviours. Barriers and enablers to adapting to T2D were explained by healthcare professionals within these parameters and, hence, as being patient-related. It was noted throughout the present study that healthcare professionals saw their role as empowering patients. However, patient-related barriers as described by healthcare professionals in the present study show a remarkable resemblance to non-empowerment based studies of healthcare professionals’ perceptions of barriers to T2D management (e.g. Brown et al. 2002). Hunt and Arar (2001) noted that healthcare professionals view self-management barriers through ‘the lens of non-adherence’. Yen et al. (2010) found that competing demands and socio-economic factors that patients saw as barriers, were considered by healthcare professionals as personal failings in their patients – e.g. poor prioritization or refusal to adhere. These studies concluded that the adherence approach placed health professionals’ understanding of managing T2D at odds with the difficulties patients experienced in managing T2D. Indeed, the adherence approach was much maligned by healthcare professionals in the present study for having expectations that were too high for the patient. One key difference between adherence studies and the present empowerment-based study is that healthcare professionals in the present study reported working clinical recommendations around their patients’ concerns, rather than expecting patients to adhere unquestioningly to clinical advice. As such, patients made choices and ‘owned’ their illness. On the other hand, patients’ concerns were fashioned into options and ‘choices’ by healthcare professionals, and instances where patients did not meet clinically recommended behaviours were seen to be a choice. Many current proponents of the empowerment approach support this assertion (Anderson, 2010).

Although seeing their practices as empowering, healthcare professionals in the present study described barriers and enablers to self-management in a similar way to healthcare professionals in studies based in the adherence approach (e.g. Brown et al, 2002). In the
present study, healthcare professionals conflated barriers which patients experienced in relation to the severity of their condition, health service provision and/or due to their social context, with barriers related to patients’ attitudes and behaviours (as per Hunt and Arar’s (2001) critique of adherence models). When adapting to living with T2D, patient participants tested the practicality of clinically-recommended behaviours by making adjustments in their day-to-day life. Barriers and enablers emerged – in different ways and at various levels - during this process. The barriers and enablers that patients and healthcare professionals reported in relation to T2D adaption in the present study were divergent at both the level at which they were seen to occur, and semantically. This divergence illustrates and provides empirical evidence to the theoretically-driven commentary on empowerment which is concerned that empowerment approaches rarely consider wider factors that mediate or moderate patient self-management, and reduce patient self-management to a ‘choice’ (e.g. Asimakopoulou, 2007; Asimakopoulou et al., 2010; Mol, 2007; Redman, 2007). Added to this, Gomersall et al., (2011) have also argued that approaches to self-management are on the whole overly-individualised – laying too much emphasis on individual behaviour - so that failures in T2D management are seen as personal failings of the patient. The above example evidences this claim, and provides an example of one way in which this individualisation process occurs.

The present study, like Asimakopoulou et al. (2011) and Scambler et al. (2012) found that healthcare professionals described social factors such as deprivation and an ageing population to be barriers to delivering empowered care. However, age alone was not found to be an important factor in the styles of management patient participants adopted or the barriers /enablers they experienced - except where age related to severity of the illness. In fact, severity of T2D was a key barrier reported by patient participants, but rarely by healthcare professionals. One reason for this may be the limits that severe T2D places on actual ability
to perform self-management behaviours and, therefore, manage in an autonomous fashion and this contradicts many of the central assumptions of the empowerment approach. The present study found that healthcare professionals did see inherent tensions in the empowerment approach – such as empowering the patient could lead to the decision to reject treatment and the potential for tokenism – which acted as a barrier to the ultimate aim of achieving clinical stability through patient self-management.

6.3. *What similarities and differences emerge in patients’ and professionals’ perceptions, understanding and experiences of managing T2D on a day-to-day basis?*

For many years the work of Cohen et al. (1994) and Hunt and Arar (2001) have set the tone for the small amount of research that exists in comparing and contrasting healthcare professionals’ and patients’ experiences of managing T2D. These studies relied on patient samples homogenized by income to demonstrate divergence healthcare professionals’ views. Both studies found that both parties used different evaluative frameworks to managing T2D. Hunt and Arar (2001) have also argued that most commonality in patient/professional views are semantically distinct, or created by healthcare professionals cross-pollinating clinical ideals to patients. The present study found that this semantic differentiation and cross-pollination did occur, and uniquely that patients also used healthcare professional encounters and health services as a gauge of self-management. The findings of the present research concur that healthcare professionals’ and patients’ evaluative contexts are on the whole divergent. However, the present research is the only piece of ‘contrast’ research which has found that patients sometimes intentionally ‘skill’ themselves in the clinical evaluative context of healthcare professionals in order to secure the best resources available to aid their
self-management. What is interesting is that this self-skilling in the clinical evaluative context is based on patients perceiving it to be a necessity of improving their care, rather than wishing to be ‘expert’ at managing their illness. Also of interest is that as patients gain more skills and become more adept in the clinical evaluative context, the more problematic they are seen to be by healthcare professionals. Hence, when similarities in evaluative contexts do occur this is not always seen to produce potentially positive outcomes, as has been the assumption of previous studies (e.g. Pooley et al, 2001).

The present research is also one of the few pieces of research to note the patient evaluative context is in itself stratified, and note how and why, patients’ perceptions, understanding and experiences are more heterogeneous than uniform. Pooley et al (2001) and Yen at al. (2010), for example, found that patients and healthcare professionals agreed that issues in health service delivery or systemic factors posed barriers to effective T2D management. A similar finding was made in the present research, one recurring example being the notion of managing finite health resources through minimal use of services. Healthcare professionals saw this as a result of increasing patient skills, whereas patients saw this as either adding to burden of self-management or as evidence that their self-management effort was ‘paying-off’ i.e. T2D management was being kept at bay, successfully delegated and so forth. Hence, this notion of using services minimally is largely agreed with, but the agreement reached in semantically distinct ways not only between the groups, but within the patient sub-groups. However, the consequences of these semantic differences have ramifications for uneven take up of services, uncertainty about how to respond to physical manifestations of T2D and delayed self-referral (Scambler, 2003; Scott et al., 2006). As this apparent consensus of ‘minimal use of service’ was also associated with managing T2D well, people with severe T2D were often portrayed as managing badly, ‘unempowerable’ and wasting healthcare resources.
Like, Fagerli et al. (2005; 2007) it was found that in some instances where role expectations acknowledged asymmetries in knowledge and power – such as when patients sought healthcare professional expertise during diagnosis – this could facilitate better understanding between the two. Equally, given the differing evaluative contexts and evidence of semantic differences in patients’ and healthcare professionals’ accounts, there is huge potential for both to spend a lot of time ‘talking past each other’ (as Skinner et al., 2007 suggests). At the same time, healthcare professionals and patients often (mis-) placed faith in one another as a matter of course. For example, a health professional can assume that a patient managing T2D to ‘keep it at bay’ is an actively empowered patient. When in reality the patient has only a didactic knowledge of T2D and contact with healthcare professionals is their sole means of gauging their self-management effort. This resonates with the work of Goyder et al (2009) where patients and healthcare professionals read their own expectations into the actions of the other. Within the contrast literature focusing on congruence and divergence in healthcare professional and patient perspectives, there has been an underlying assumption that congruence is ‘good’ and divergence is ‘bad’. However, when we look at the quality of understanding in these relationships discussed so far, the central assumption of ‘partnership’ at the heart of empowerment into thrown into disarray. This partnership approach at the heart of empowerment, attempts to disaggregate and divide ‘expert’ and ‘lay’ knowledge to level out status differentials (Asimakopoulou, 2007), but also creates the potential for role expectations where healthcare professionals and patients can regularly misplace faith and talk past one another. ‘Contrast’ approaches focusing on divergence and congruence can highlight different evaluative contexts, and sometimes semantic divergence. But only through looking at differences in the ways patients and healthcare professionals realise their T2D-management concerns through engagement with their social contexts that we can understand
how their role expectations in relation to one another, and their social contexts shape their management of T2D.

6.4. **Methodological strengths and limitations of the present study**

A strength of the present study was the use of a critical realist epistemological foundation. The critical realist approach successfully allowed data-collection and analysis to focus on and distil the interaction between socio-contextual issues (such as health service provision, socio-economic factors, and social support) and individual, phenomenological experiences (e.g. how patients integrate T2D into daily routines or healthcare professionals’ motives for practising empowerment) without reducing causal explanations to either level of analysis (Willig, 2008). Hence, the present study offered a cross-sectional snapshot of how T2D is managed by both patients and healthcare professionals, and demonstrated how their day-to-day actions were shaped by striking a balance between personal concerns and factors in their social contexts. This mediation process is common in the literature, for example, concepts such as fitting the ‘impingement’ of T2D on day-to-day life (Kelleher, 1998), adoption of a ‘diabetic identity’ (Ockleford, 2007), how self-care responsibility is divided between self and others (Hunt et al., 1998; Collins et al., 2009) and managing T2D through balancing well-being against biological health (Maclean, 1991). However, the aforementioned studies explore these central constructs as proximal factors which shape a person’s capacity to engage ‘successfully’ with T2D self-management. Therefore, barriers and enablers to self-management are either reduced to the ability of the individual to act, or seen as occurring distally by thwarting or enabling the individual’s capacity to act. The critical realist approach allowed the researcher to acknowledge that people who have a long-term illness which affects their body, have wider personal concerns, but live in a stratified society which shapes the resources available in their social contexts. As such, the central constructs people use to
realise and use to gauge un/successful management can vary according to this stratification, as can the barriers and enablers they experience. The use of this epistemological framework to analyse both healthcare professional and patient accounts, allowed for direct contrast and comparison. This suggests that there is strong potential for theoretical generalisation or ‘transferability’ (Lewis and Ritchie, 2006) from this aspect of the study methodology, i.e. wider replication, application and testing of the theoretical principles underpinning the present study in other research.

However, the external validity, or ‘transferability’ of the findings may be limited by the capacity to draw inferential generalisations from some aspects of the study (Lewis and Ritchie, 2006), i.e. the ability to generalise from the context of the research itself to other situations and settings. The unique, nascent nature of the Diabetes Participation Group as a source of patient empowerment at the time of the research means the findings may be unique (in terms of setting) to this specific group. Equally, there may be ‘empowered’ patients and/or healthcare professionals practicing empowerment in the Borough who may not be members of the group, and may have wholly different experiences of managing T2D. Another limitation, as discussed, in the earlier profile of participants, was a lack of Asian respondents recruited to the study. Although partially due to the low prevalence of Asian communities in the Borough where the research occurred, this limitation may underplay the role of culture in shaping self-management practices (particularly through the individual’s social context) which has been shown in previous studies (e.g. Kokanovic and Manderson, 2007 and Peek et al, 2010). These limitations could affect the inferential generalisability of the findings, e.g. transferability of the research findings to this aspect of the T2D population and T2D healthcare professionals. However, previous research has found that culture is an antecedent, or confounding variable of socio-economic factors in patient self-management (Brown et al., 2004; Fagerli et al., 2007) suggesting that this a mediator within the process of self-
management that would add to, rather than substantially alter, the processes and categories found in the present study.

The group was led by the local NHS trust, and all members were self-selecting and opted into the research. All people managing T2D in the borough were invited to take part in the group by healthcare professionals. This could mean that the patients and healthcare professionals had not only self-selected to be group members, but had also opted to take part in the research, because they held strong views about such things as how T2D should be managed, health service delivery, or patient empowerment. However, the present study used multiple methods of data-collection designed to capture infrequent attendees in the patient population (who may look less favourably on the group), and sampling healthcare professionals with experience of practising in an empowering fashion was a key aim of this sample selection strategy (and different degrees of support and scepticism of empowered T2D management were evident in their accounts).

Overall, there were clear benefits and advantages in sampling through this, or any other, Participation Group. The sampling strategy successfully captured a heterogeneous sample of people in the borough, and captured the group most likely to be living with T2D - older people 60+ - and within this produced a heterogeneous sample of people living with T2D with regards to living arrangements, education, annual income, time since diagnosis and severity of the condition. Equally, the healthcare professional sample was varied by occupational role. Purposively selecting the group as a sample not only ensured an organically heterogeneous sample, but it also ensured that previous contact between the patient and healthcare professional participants had occurred. As such, both groups reported perceptions, understanding and experiences of (empowered) T2D management using the same social and healthcare contexts. This suggests there is strong inferential generalisibility (‘transferability’) to the central aspect of the study – the contrast and comparison between
healthcare professionals’ and patients’ perceptions, understanding and experiences of empowered T2D management.

Various strategies (described in detail in the methodology section) were employed to increase the internal validity or ‘credibility’ in the collection and analysis of data – i.e. whether the data was an accurate reflection of the perceptions of the participants’ views and experiences. The strategies were: 1) prolonged engagement and persistent observation in the field; 2) deviant case analysis to include all views; 3) member validation - soliciting participants’ views of the credibility of the findings and interpretations; 4) clarifying researcher bias and employing reflexive awareness from the outset of the study 5) rich and thick description; and 6) triangulation of data by data-collection methods during data analysis; 7) use of multiple coders (Cresswell, 2007).

Reflexivity is an awareness of the ways a researcher’s identity and background can impact upon data-collection and analysis. There was potential for the researcher to affect the research due to his background (as outlined in the methodology section). Especially, when working in a socially diverse, deprived area with a T2D group comprised predominantly of older people. As such, there was a potential for both perceived and actual power differentials relating to class, age, ethnicity and gender with patient participants. To minimise this, it was made clear to patient participants that the researcher was independent, not a healthcare professional nor employed by the NHS, and the treatment and services they received would not be affected by taking part in the study - and that it was their perception and experience that was sought. Equally, the researcher was a sociologist and not a medical expert in diabetes, and had limited experiences of observing the use of T2D-related health services, which may impact on the interpretation of the data. However, participants were given the chance to comment on how the data had been interpreted in feedback sessions. Another reflexivity factor, was that the researcher’s and supervisors’ own works in this area were included, epistemological
reflexive monitoring (the unity of theory approach in critical realism) was employed to reduce bias in analysis (Willig, 2008).

The cross-sectional design of the study may place limitations on the reliability (trustworthiness) of the data gathered on patient participants’ accounts of diagnosis and some of the material on adaption. For example, Lawton et al. (2008:54) note that “…people’s pasts will change in conjunction with their presents…” Therefore, although patient participants were asked to recall as accurately as possible their experiences of diagnosis, deteriorating recall of events may have occurred, and/or their accounts may have been shaped by their current experiences. Counter to this, and as found in the literature review chapter, Polonsky et al.’s (2010) study of the long term effects of diagnosis found no differences in findings when comparing patient accounts of diagnosis with length of time since diagnosis –suggesting that deteriorating recall of events is not a feature of patients’ retrospective accounts of diagnosis. This potential limitation should also be traded off against the pitfall of longitudinal studies of T2D diagnosis which have consistently used homogenous samples of newly-diagnosed (usually asymptomatic) patients’ experiences (Peel et al., 2004; Lawton, 2005). For example, the present study found an additional route to diagnosis by using a cross-sectional heterogeneous sampling method that incorporated patients whose T2D had progressed to varying degrees of severity. Equally, the findings of the present study also reflect the findings of longitudinal studies (e.g. patients reading into healthcare professionals’ delivery of diagnosis, and diagnosis rarely being a ‘shock’ for patients) again suggesting that retrospective reporting did not affect the accuracy of the data.

Another potential limitation was that healthcare professionals in the present study worked for the trust which funded the group, and were often founding members of the group. Thus, healthcare professional accounts may be tainted by wishing to present their work in a positive light. All participants were assured their responses were confidential (and would be
anonymised) and responses in the healthcare professional sample were positive and critical in equal measure both within, and between, accounts.

6.5. **Areas for further research**

Given that many patients were fearful of their symptoms whilst others self-diagnosed, the area of the acceptability and effectiveness of T2D self-diagnosis, outside of clinical settings, is an area requiring further research. Another area of research emerges almost through omission, this is the lack of any data on healthcare professionals’ views of how patients adapt to living with T2D. Given that patients saw it as a continuous recursive process, it is important to explore why healthcare professionals tend to see the process as a temporary short-lived state - of little independent significance yet - claim to incorporate patients’ views into their decision-making. One area which was explored in a limited fashion, due to the co-interview format, was co-carers’ experiences of managing T2D - understanding the balances that co-carers face in managing T2D will highlight how the individualised concept of empowered ‘self-management’ is at odds with the way people often co-manage T2D in reality. The typology of self-management styles show potential for testing in a quantitative fashion. Given the multiple factors seen to inform these styles of self-management it is possible to quantify these into different variables and test associations, as well gauge these against clinical indicators.

In overview, we have seen that T2D management is shaped by the interaction between social contextual factors and stage of disease in the case of patients. Conversely, T2D management was largely an issue of marrying together patient needs, healthcare resources and addressing social change using the empowerment approach for healthcare professionals. Using the critical realist approach we were able to explore how different levels of T2D management are interpreted, responded to, and used by healthcare professionals and patients. It was also
possible to explore how these levels; the different measures T2D management success and barriers/enablers were inter-related. This makes the present study unique in its approach and builds on and adds to existing research.

6.6. **Practical applications of the work**

1) The first practical application of this research stems from the differences in experiences and perceptions of diagnosis reported by patients and healthcare professionals. It is crucial that information is tailored to each patient according to the route to diagnosis, and that the uncertainties patients’ experience following diagnosis are addressed through healthcare professional consultation with the patient, before self-management is promoted.

2) Establishing the acceptability to patients, and the ability and potential accuracy of patients to self-diagnose T2D through feasibility studies would go some way to establish whether this is a way to deal with the ‘clinical iceberg’ in undetected T2D prevalence.

3) Patients detailed accounts of their experiences of adaption highlighted how adaption was a process of ‘fitting T2D’ into their day-to-day social contexts. In contrast, healthcare professionals regarded adaption as a process of individual behaviour change, and attempted to usher patients towards full self-management. As part of their training, healthcare (and other welfare) professionals should be made aware of how wider social factors and economic resources can shape a person’s capacity to self-manage T2D, and that adaption may occur recursively over long periods of time. Healthcare (and welfare professionals) may then be able to work together with patients to help overcome barriers which patients experience, and allow for healthcare
professionals to facilitate enabling services and environments – rather than focussing on, and often mislabelling, barriers to self-management as being patient-related.

4) Information provision for those self-managing should be designed and tested to ensure that it contains didactic, instructional clinical information as well as information that assists patients in orientating and navigating health services. This information should also be varied in complexity to allow for gradation according to patient preference, stage of the illness and so that more complex information can be introduced over time to improve patient self-management of T2D. However, information should NOT become a replacement for one-to-one guidance from healthcare professionals which was valued by the majority of patients in this study.

5) The typology of self-management styles identified in this study should be tested in a quantitative fashion. Quantifying the different variables found in the study (motives for self-management, information use), and the clusters of styles can be used to identify patient need as well as be tested against clinical indicators of self-management outcomes.

6) Patient participants equated successful T2D self-management with minimal use of health services, equally they experienced uncertainty about when professional help should be sought and regulated their use of health services as they felt that there were ‘other people’ in greater need. This suggests that healthcare professionals should provide clear guidance to patients which establishes what falls within the remit of patient ‘self-management’ and when it is appropriate to self-refer.

7) Amongst healthcare professionals the concept of empowerment was seen as a malleable concept. Hence, systematic concept clarification of the meaning and ‘reach’ of empowerment is required, e.g. is health service resource control an intended or unintended outcome of ‘patient empowerment’? Are healthcare professionals the best arbiters of empowerment given the need to control health resources? Further research
and policy analysis exploring how healthcare professionals mediate between ‘empowering patients’ and ‘controlling health resources’ (and the outcomes of this process) are required. The findings of this research suggest that healthcare professionals’ and patients’ views and perspectives should be considered and incorporated into this policy debate.
Conclusion

The overarching aim of the present research was to compare and contrast the perceptions, understanding and experiences of patients and healthcare professionals who managed T2D within a healthcare context where empowerment was the prevailing paradigm.

In meeting this aim, the first research question explored barriers and enablers to T2D management from the patient and healthcare professional perspective. Previous studies have tended to list or describe the types of barriers and enablers that patients and healthcare professionals experienced. The present research described the process whereby the barriers and enablers to T2D management experienced by patients and healthcare professionals are shaped by integrating T2D management within their existing personal, healthcare and socio-contextual circumstances.

The second research question explored how patients and healthcare professionals gauged successful and unsuccessful management of T2D. Patients applied and fitted T2D self-management within their day-to-day lives, and the factors they used to gauge the success of their effort reflected their social context. Healthcare professionals, on the other hand, used the empowerment approach to marry together their disparate concerns relating to patient need, healthcare system resources and social change. As such, healthcare professionals’ gauges of un/successful management were informed largely by their practice of empowerment.

The final research question compared and contrasted patients’ and healthcare professionals’ perceptions, understanding and experiences of T2D management and found that patients and healthcare professionals managed T2D using different evaluative contexts and criteria. Hence, it was found that healthcare professionals’ and patients’ accounts of managing T2D were largely at odds with one another.

In addressing these research questions key findings emerged, these are listed below.
Patients arrived at diagnosis in different ways and with different understandings of how and why they got there;

The way that a diagnosis point is reached affects how people understand their diagnosis and how they initially adapt to living with T2D;

Once a diagnosis is made patients need to adapt to or make space for the diagnosis and its consequences in their daily lives before they can start to self-manage;

Once a diagnosis is given healthcare professionals decide how best to provide individualised information to their patients. There is little space for a process of adaption, but a straight move from diagnosis to information to self-management;

Healthcare professionals perceive self-management as the process through which patients are given sufficient information to manage their condition. Their view is that information should be given in an individualised way with the aim of successful self-management — i.e. patients meeting clinical targets by following clinically recommended behaviours;

Patients have different understandings of, and aims for, their self-management which depend on the social context within which people are managing their condition.

Six different styles of patient self-management were identified, these were:

- Self-managing T2D through routinisation;
- Self-managing T2D as a burden;
- Self-managing T2D as keeping T2D at bay;
- Self-managing T2D through delegation;
- Self-managing T2D through co-management;
- Self-managing through autonomy.

These styles have different criteria for success meaning that patient self-management of T2D is not a uniform concept, but comprised of range of different concepts each with their own rationale and criteria for success;
There is a fundamental mismatch between patients and HCPs with regards to the process, aims and criteria for success in self-management of T2D. It was found that where patients can reflect healthcare professionals’ criteria for successful T2D management they reported being able to leverage healthcare resources they needed.

Overall this thesis has demonstrated that patients’ and healthcare professionals’ experiences of managing T2D are moderated by the agenda each one brings into their interaction, and that often these two groups of people start from different points, and aim to achieve different outcomes - yet work within a healthcare system where there is an expectation that they will form a partnership and achieve targets the attainment of which depend upon the context they each find themselves in.
Bibliography


Department of Communities and Local Government’s Index of Deprivation (2007) Indices of Multiple Deprivation 2007. London: Department of Communities and Local Government Available at:


Department of Health (2008) Health Profile 2008. London: Association of Public Health Observatories [Internet]. PDF Available at:


FEND – Federation of European Nurses in Diabetes et al. (2011) Diabetes, The Policy Puzzle: Is Europe making progress. Available at:

http://www.fend.org/projects/policy-puzzle

(Accessed on 16/07/2013)


Jowsey, T., Gillespie, J., and Aspin, C. (2011) Effective communication is crucial to self-management: The experiences of immigrants to Australia living with diabetes


Kitzinger, J. (1994). The methodology of Focus Groups: the importance of interaction between research participants. Sociology of Health & Illness, 16(1), 103-121.


Lawton, J., Ahmad, N., Hanna, L., Douglas, M., Bains, H., Hallowell, N. (2008b) 'We should change ourselves, but we can't': Accounts of food and eating practices amongst British Pakistanis and Indians with type 2 diabetes. Ethnicity and Health, 13 (4), pp. 305-319.


NHS Diabetes (2013) Best practice for commissioning diabetes services - An integrated care framework Available at:


    (Accessed 09/01/2013)

NHS National Diabetes Service (2012) NHS atlas of variation in healthcare for people with diabetes. Available at:

    http://www.rightcare.nhs.uk/index.php/atlas/diabetes

    (Accessed 18/07/2013)


XXXXXXXX Council (2005) Historic XXXXXXXX: History and Context.(online). Available at:


3 XXXXXXXX – redacted for purposes of anonymity


Appendix One: Literature review supplements

Appendix 1a: Literature review search terms
## Appendix 1a) Literature review search terms

<table>
<thead>
<tr>
<th>Index Term</th>
<th>Synonyms</th>
<th>Related Terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Type 2 Diabetes</td>
<td>1a) Type 2 Diabet*</td>
<td>N/A</td>
</tr>
<tr>
<td>2. Health* professional*</td>
<td>2a) Health* providers; 2b) Health* practitioners; 2c) providers; 2d) practitioners</td>
<td>2e) GPs 2f) General Practitioners 2g) Doctors 2h) Nurs* 2i) Dietician 2j) Podiatr* 2k) Pharma*</td>
</tr>
<tr>
<td>3. Patients</td>
<td>3a) People living with Type 2 Diabet*</td>
<td>3b) Type 2 Diabet* population</td>
</tr>
<tr>
<td>4. Experience</td>
<td>4a) Practice</td>
<td>4b) Manag* 4c) Self-manag*</td>
</tr>
<tr>
<td>5. Perceptions</td>
<td>5a) Views</td>
<td>5b) Understanding* 5c) Attitudes 5d) Knowledge</td>
</tr>
<tr>
<td>6. Contrast*</td>
<td>a) Compar*</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Search strategy 1 (Contrast studies):


Search strategy 2 (Patients’ experiences):


Search strategy 3 (Healthcare professionals’ experiences):


Table 9: Table of literature review terms and search strategy
Appendix Two: Data-collection supplements

Appendix 2 a: Introductory cover letter for patient participants
Appendix 2 b: Patient participant information sheet (for questionnaires, focus groups and interviews)
Appendix 2 c: Consent form (all patient and healthcare professional participants)
Appendix 2 d: Topic guide for patient participant focus groups
Appendix 2 e: Topic guide for patient participant interviews
Appendix 2 f: Patient participant questionnaire
Appendix 2 g: Patient participant ‘About you’ sheet (for gathering questionnaire, focus group and interview participants’ socio demographic data)
Appendix 2h: Introductory cover letter for healthcare professionals
Appendix 2 i: Healthcare professional participant information sheet
Appendix 2 j: Topic guide for healthcare professional participant interviews
Appendix 2 k: Research questions with pathway to corresponding data collection tool question number (and comparable questions)
Appendix 2 a: Introductory cover letter for patient participants

Dear Sir or Madam,

We are writing to you, as a member of [Name] Diabetes Participation Group, to ask for your help with a research study investigating the role of self-management approaches in Type 2 Diabetes treatment and care.

As you may be aware, self-management approaches are growing in all areas of healthcare, including Type 2 Diabetes. This research seeks to investigate this trend by exploring how people manage Type 2 Diabetes in their day-to-day lives.

The research is working closely with all [Name] Diabetes Participation Group members’, as well as practitioners in local Health Trusts to ensure a variety of perspectives are incorporated. The research will be looking for similarities and differences in patients’ and healthcare professionals’ experiences of self-management. The research would benefit from your unique insight and experiences gained from living with Type 2 Diabetes.

Further information is provided in the Participant Information Sheet (attached). Please take time to read this before deciding whether to participate. However, please remember that your response (or non-response) will be treated with utmost confidentiality.

Thank you for taking the time to read this, and thank you in advance should you choose to participate at any stage of the research process.

Yours Sincerely

[Signature]

Paul Newton
Appendix 2 b: Patient participant information sheet (for questionnaires, focus groups and interviews)

Participant Information Sheet

Name of Study: Comparing and contrasting patients’ and healthcare professionals’ experiences of self-management

Local Research Ethics Committee Ref: 06/Q0703/137

Name of Researcher: Paul Newton

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

Self-management approaches are growing in all areas of healthcare, including Type 2 Diabetes. This research seeks to investigate this trend by exploring how people manage Type 2 Diabetes in their day-to-day lives. Over the past 20 years patients have been more involved in personally managing long-term conditions such as Type 2 Diabetes. In fact, the government, as well as health and social care workers, now actively encourage the approach as it is seen to be a good way to meet peoples’ needs.

Most of the current research in the self-management has looked at the ways in which people can become more involved in helping themselves and their loved ones. The aim of this study is to explore experiences of patient self-management and how healthcare professionals manage Type 2 Diabetes.

Why have I been chosen?

Being a member of [Name] Diabetes Participation group lends you invaluable, first-hand experience of the self-care approach. The researcher also wants to gather a wide range of views and opinions on this topic so people of different ages, both genders and from different social backgrounds have been invited to take part in this study.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

You can decide how you take part. Everybody in the group will be invited to attend a focus group with other members of your group. Whether you decide to take part in a focus group or not, you can still opt to also do a one-to-one interview OR fill out a questionnaire in your own time and return it in the pre-paid reply envelope by April 30. All the options are listed below. You can:
• Attend a focus group only
• Fill out a questionnaire only
• Be interviewed on a one-to-one basis only.
• Attend a focus group and then fill out a questionnaire
• Attend a focus group and then be interviewed on a one-to-one basis

If you choose to do an interview, book early, as there are only 40 interview slots on a first-come-first-served basis. Interviews are popular as you can discuss issues in-depth with complete confidentiality. These interviews can be arranged at a time and place convenient to you, or at an appropriate room at Kings College London if you prefer.

People choosing a one-to-one interview will also have the opportunity to invite two friends, relatives or carers, who have experience of diabetes or its treatment and care, to participate.

The total time for your involvement in the study depends on you:

• Focus groups will last around two hours with a 15 minute comfort break in the middle.
• One-to-one interviews will last around one hour
• You have up to three months to fill out and return your questionnaire which should take around 30 minutes.

You will be reimbursed all travel costs related to your involvement in the study.

**Will my taking part in this study be kept confidential?**

Nothing that you tell the researcher in the focus group, interview or questionnaire will be passed on to anyone else. In focus groups the same regulations that apply to your current group regarding confidentiality will apply. If you decide to take part in a face-to-face interview with the researcher or a focus group - the session will be tape recorded. Any recorded information will be written up and all names removed to ensure anonymity - and then the recorded copies will be destroyed. If you choose to fill out a questionnaire, you have the option of giving your details to us in order to be invited to a feedback session (about the research) at a later date. These details will be separated from your questionnaire and the information will only be available to the researcher.

**What will happen to the results of the research study?**

The results of this research will be used for a PhD degree. A copy of the results will be available from the chief researcher if you wish to see them.

**Who has reviewed the study?**

The study has been reviewed by Kings College Hospital Research Ethics Committee.

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**Thanks again for taking time to read this.**

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Appendix 2 c: Consent form (all patient and healthcare professional participants)

Consent Form

Name of Study: Comparing and contrasting patients’ and healthcare professionals’ experiences of self-management

Local Research Ethics Committee Ref: 06/Q0703/137

Name of Researcher: Paul Newton

Please complete this form after you have read the Participant Information Sheet (enclosed) and listened to an explanation about the research.

Local Research Ethics Committee Ref: [fill]

Name of Researcher: Paul Newton

- Thank you for considering to take part in this research. The person organizing the research must explain the project to you before you agree to take part.

- If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Please tick, if you agree with these statements:

- I understand that if I decide at any other time during the research that I no longer wish to participate in this project, I can notify the researchers involved and be withdrawn from it immediately without giving any reason - without my medical care or legal rights being affected.

- I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Participant’s Statement:

I ______________________________________________________________________________________________

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed: ___________________________________________ Date: __________________________

Investigator’s Statement:

I ______________________________________________________________________________________________

confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the volunteer.

Signed: ___________________________________________ Date: __________________________
Appendix 2 d: Topic guide for patient participant focus groups

Topic Guide for Focus Groups

Name of Study: Comparing and contrasting patients’ and healthcare professionals’ experiences of self-management

Local Research Ethics Committee Ref: 06/Q0703/137

Name of Researcher: Paul Newton

Topic Guide - Focus Groups

Prior to beginning session:

1.) Time to read information sheet if participant hasn’t already.
2.) Obtain consent
3.) Reiterate the key elements of information sheet

Preamble:

Please remember that your answers are anonymous and confidential. Similar to when you attend Participation Group meetings, we ask you to respect other people’s confidential information. The researchers on this study are the only people who have access to your answers. The session will be tape recorded but you can ask for the tape recorder to be switched off at any point. Most importantly – Please remember that there are NO right or wrong answers to the questions. What we are most interested in is your experiences and opinions.

First I will be asking some questions about when you were diagnosed diabetes, how you responded to this news and how you manage it day-to-day currently. At the end will ask you to fill out a form to give some information about you.

Introduction

a) Please can you say your name and how long have you have been living with Type 2 Diabetes:

Diagnosis

b) How were you diagnosed?

c) Can you recall, as accurately as possible, how you responded to you diagnosis?

d) How did your friends and family respond to the news?

e) What help and support did you receive when you were diagnosed?

(Prompts: Healthcare professionals, family and friends, information, other organisations? Is there anything you found particularly helpful?)

f) Would you improve anything about how you were diagnosed?
Adaption to living with T2D

g) How has your life changed since diagnosis (and now)?

h) Did you experience any challenges in getting used to living with T2D?

i) Is there anything that helped you to adapt to living with T2D?

Managing T2D on a day-to-day basis

j) Does having diabetes place any restrictions on you?  
   (Prompt other illnesses and T2D severity?)

k) What do you find helps you to manage your condition?

l) What type of help and support do you receive at the moment?

m) How do you know if you are managing successfully?

n) So, how do you know if you are managing unsuccessfully?

Information

o) What type information do you find useful?  
   (Prompt: Why? Where do you get it from?)

About the group

p) When and why did you begin to attend the participation group?

q) What happens in the group, why do you attend?

Closing

r) What other questions do think should have been asked about living with Type 2 Diabetes?

s) Is there anything that anybody would like to discuss which hasn’t already been discussed?

Thank participants for taking part.

Request participants to fill in ‘About You’ sheet.
Appendix 2 e: Topic guide for patient participant interviews

<table>
<thead>
<tr>
<th>Topic Guide for patient participant interviews</th>
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</thead>
<tbody>
<tr>
<td>Name of Study: Comparing and contrasting patients’ and healthcare professionals’ experiences of self-management</td>
</tr>
<tr>
<td>Local Research Ethics Committee Ref: 06/Q0703/137</td>
</tr>
<tr>
<td>Name of Researcher: Paul Newton</td>
</tr>
</tbody>
</table>

Prior to beginning session:

4.) Time to read information sheet if participant hasn’t already.
5.) Obtain consent
6.) Reiterate the key elements of information sheet

Preamble:

Please remember that your answers are anonymous and confidential. The researchers on this study are the only people who have access to your answers. The session will be tape recorded but you can ask for the tape recorder to be switched off at any point. Most importantly – Please remember that there are NO right or wrong answers to the questions. What we are most interested in is your experiences and opinions.

First I will be asking some questions about when you were diagnosed diabetes, how you responded to this news and how you manage it day-to-day currently. At the end will ask you to fill out a form to give some information about you.

Introduction

a) How long have you have been living with Type 2 Diabetes? (Years and months)

Diagnosis

b) How were you diagnosed?

c) Can you recall, as accurately as possible, how you responded to you diagnosis?

d) How did your friends and family respond to the news?

e) What help and support did you receive when you were diagnosed?

(Prompts: Healthcare professionals, family and friends, information, other organisations? Is there anything you found particularly helpful?)

f) Would you improve anything about how you were diagnosed?
Adaption to living with T2D

g) How has your life changed since diagnosis (and now)?

h) Did you experience any challenges in getting used to living with T2D?

i) Is there anything that helped you to adapt to living with T2D?

Managing T2D on a day-to-day basis

j) Does having diabetes place any restrictions on you?
   (Prompts: How T2D is prioritised, competing priorities? why restrictive? When?)

k) What do you find helps you to manage your condition?

l) What type of help and support do you receive at the moment?
   (Prompts: Healthcare professionals, family and friends, information, other organisations)

m) How do you know if you are managing successfully? (Prompt for examples)

n) So, how do you know if you are managing unsuccessfully? (Prompt for examples)

o) Have you experienced any complications, or are you managing any other long-term illnesses?

Information

p) What type information do you find useful?
   (Prompt: Why? Where do you get it from?)

About the group

q) When and why did you begin to attend the participation group?

r) What happens in the group, why do you attend?

Closing

s) What other questions do think should have been asked about living with Type 2 Diabetes?

t) Is there anything that anybody would like to discuss which hasn’t already been discussed?

Thank participants for taking part.

Request participants to fill in ‘About You’ sheet.
Appendix 2 f: Patient participant qualitative questionnaire

Patient participant questionnaire

Name of Study: Comparing and contrasting patients’ and healthcare professionals’ experiences of self-management

Local Research Ethics Committee Ref: 06/Q0703/137

Name of Researcher: Paul Newton

Kings College London

Questionnaire – Group members

Thank you for agreeing to help us with our study. Please ensure that you have read and understood the Participant Information Sheet and signed your Consent form. Please remember that only the researchers will know what you have written and all data will be treated as confidential.

This questionnaire is divided into six sections as follows:

- Section 1 asks questions relating to your experience of being diagnosed with Type 2 Diabetes;
- Section 2 enquires about how you adapted to living with Type 2 Diabetes;
- Section 3 is related to living with and self-managing Type 2 Diabetes.
- Section 4 asks questions about where you get information and taking part in the participation group;
- Section 5 gives you an opportunity to write about anything you feel is relevant to the study but is not covered in the above sections.
- Section 6 asks background information about you.

You can write as much or as little as you like. Where you continue on another sheet, please number your comments with the relevant section number and question number (e.g. - Qa).

The closing date for reply is 30 April, 2007, please find enclosed the stamp addressed envelope for your reply. If you have any further questions relating to the questionnaire do not hesitate to contact us – Contact details are given at the end of the participant information sheet.

Most importantly – Please remember that there are NO right or wrong answers to the questions. What we are most interested in is your experiences and opinions.

Please try to answer each question as fully as possible.
Section 1. About Type 2 Diabetes & your diagnosis:

   a) How long have you have been living with Type 2 Diabetes? *(Years and months)*

   [ ] Years   [ ] Months

   b) How were you diagnosed? *(Did you have any symptoms? Who gave you the news?)*

   (Continue on a separate sheet, if necessary)

   c) Can you recall, as accurately as possible, how you responded to you diagnosis?

   (Continue on a separate sheet, if necessary)

   d) How did your friends and family respond to the news?

   (Continue on a separate sheet, if necessary)
e) What help and support did you receive when you were diagnosed?
(e.g. from healthcare professionals, family and friends, information, other organisations? Is
there anything you found particularly helpful?)
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f) Would you improve anything about how you were diagnosed?
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Section 2: Adaption to living with T2D
g) How has your life changed since diagnosis (and now)?
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h) Have you experienced any challenges in getting used to living with Type 2 Diabetes?

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(Continue on a separate sheet, if necessary)

i) Is there anything that has helped you to adapt to living with Type 2 Diabetes?

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Section 3: Managing T2D on a day-to-day basis

j) Does having diabetes place any restrictions on you?

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(Continue on a separate sheet, if necessary)
k) **What do you find helps you to manage your condition?**

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l) **What type of help and support do you receive at the moment?**

(e.g. from healthcare professionals, family and friends, information, other organisations? Is there anything you found particularly helpful?)

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m) **How do you know if you are managing your condition successfully? (Please provide examples)**

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n) How do you know if you are managing your condition unsuccessfully? (Please provide examples)

(Continue on a separate sheet, if necessary)

o) Have you experienced any complications, or are you managing any other long-term illnesses?

(Continue on a separate sheet, if necessary)

Section 4: Using information and attending [NAME] Participation Group

p) What type information do you find useful? (Why is it useful? Where do you usually look for information?)

(Continue on a separate sheet, if necessary)
q) When and why did you begin to attend the participation group?

r) What happens in the group, why do you attend?

Section 5: Anything else?

s) What other questions do think should have been asked about living with Type 2 Diabetes?

t) Is there anything that anybody would like to discuss which hasn’t already been discussed?

Thank participants for taking part.

Now please fill in ‘About You’ sheet overleaf.
The information gathered here is ABOUT YOU.

This information is gathered to ensure that the researcher has gathered a range of opinions, and to ensure that different types of people are represented in the study. The data will only be used anonymously and only the research team will have access to this data.

a) How old were you on your last birthday:

Are you: Male ☐ Female ☐

b) To which of these ethnic groups do you consider you belong? (Tick one only)

White: ☐

Mixed heritage:
White and Black Caribbean ☐
White and Black African ☐
White and Asian ☐
Any other Mixed background ☐

Asian or Asian British Indian: ☐
Pakistani ☐
Bangladeshi ☐
Any other Asian background ☐

Black or Black British Caribbean:
African ☐
Any other Black background ☐

Chinese: ☐

Any other ethnic group (Please Describe) ☐

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c) What is your marital status? (Please tick)

Single ☐
Separated/Divorced ☐
Married ☐
Widowed ☐
Living with partner ☐
Other ☐
(Please Describe) ☐

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d) How many people are there in your household?

Adults ………… Their relationship to you …………………………………………………

Children ……… Their relationship to you …………………………………………………

e) What level of education have you achieved? (Please tick)

Primary school □
Secondary school □
Vocational or professional qualification □
Diploma □
University Degree □
Postgraduate Qualification □

f) What is your average household income per year after income tax? (Please tick)

£0-1000 □
£1001-3000 □
£3001-6000 □
£6001-10,000 □
£10,001-15,000 □
£15,001-21,000 □
£21,001-28,000 □
£28,001-36,000 □
£36,001-45,000 □
£55,001-66,000 □
£66,001-78,000 □
£78,001-91,000 □
£91,000+ □

If you wish to be contacted at a later date for a feedback session about the research, please fill in this section and we will send you an invitation through the post:

Name: ……………………………………………………………………………………………

Address: ………………………………………………………………………………………
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Thank you for your participation.
Dear [NAME],

We are writing to you to ask for your help in a research study investigating the role of self-management approaches in diabetes treatment and care.

As you may be aware, self-management approaches are being promoted in all areas of healthcare, including diabetes and in many healthcare professionals also adopt an empowerment framework to help patients to self-manage. This research seeks to investigate this trend by exploring how empowered self-management is practiced by healthcare professionals in their day-to-day management of Type 2 Diabetes, and compare this with patients’ experiences.

The research is also working closely with members of the Participation Group in [Name] and their families and carers to ensure a variety of perspectives are incorporated. We would be most grateful if you would agree to be interviewed about your experiences; this will take about 30-60 minutes.

Further information is provided in the Participant Information Sheet (attached). Please take time to read this before deciding whether to participate. However, please remember that your responses (or non-response) will be treated with utmost confidentiality and in an anonymous fashion. All responses will not be reported in any way that allows the individual to be identified.

Thank you for taking the time to read this, and I thank you in advance should you choose to take part. I will be contacting you within the next two weeks to see if you wish to take part and to arrange a time to meet. Please contact me using the contact details above if you do not want to be contacted about this study.

Yours Sincerely

Paul Newton
Appendix 2 i: Participant information sheet for healthcare professional participants

**Participant Information Sheet – Healthcare professionals**

**Name of Study:** Comparing and contrasting patients’ and healthcare professionals’ experiences of self-management

**Local Research Ethics Committee Ref:** 06/Q0703/137

**Name of Researcher:** Paul Newton

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

**What is the purpose of the study?**

Over the past 20 years patients have been more involved in planning and providing care in the NHS. In fact, the government, as well as health and social care workers, now actively encourage self-management approaches as it is seen to be a good way to meet peoples’ needs.

The aim of this study is to explore, compare and contrast patients’ and healthcare professionals’ experiences of self-management and managing Type 2 Diabetes.

**Why have I been chosen?**

The researcher is already working closely with patient members of the Diabetes Participation Group in [Name], of which you are a healthcare professional member, to record their experiences of the self-management. However, your first hand experience of Type 2 Diabetes treatment and care lends you invaluable, first-hand experience of the of the issues encountered in practice that would be invaluable to this study.

The researcher also wants to gather a wide range of views and opinions on this topic so professionals from a range of disciplines in the Trust have been invited to take part in this study. Your details were found using information that is already in the public domain, such as searching the [Name] PCT website. Patient and healthcare participants views will be compared and contrasted to explore similarities and differences.

**Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

**What will happen to me if I take part?**

You will be invited to take part in an interview lasting about 30-60 mins. You will also be asked to sign the attached consent form so that your contribution can be included in the study.
Will my taking part in this study be kept confidential?

When you choose to agree to an interview, you have the option of giving your details to us in order to be invited to a feedback session (about the research) at a later date. These details will be separated from your interview data and the information will only be available to the researcher.

What will happen to the results of the research study?

The results of this research will be used for a PhD degree. A copy of the results will be available from the chief researcher if you wish to see them.

Who has reviewed the study?

The study has been reviewed by Kings College Hospital Research Ethics Committee.

Thank you again for taking time to read this.

Contacts for further information:

Paul Newton
Department of Dental Public Health
Dental Institute
Caldecot Road
Denmark Hill
London
SE5 9RW
T: 0203 299 3481
F: 0203 299 3409
E: paul.4.newton@kcl.ac.uk

OR:

Dr Sasha Scambler
Department of Dental Public Health
Dental Institute
Caldecot Road
Denmark Hill
London
SE5 9RW
T: 0203 299 3481
F: 0203 299 3409
E: sasha.scambler@kcl.ac.uk
Name of Study: Comparing and contrasting patients’ and healthcare professionals’ experiences of self-management

Local Research Ethics Committee Ref: 06/Q0703/137

Name of Researcher: Paul Newton

Interview Schedule – Healthcare Professionals

Prior to beginning interview:

1.) Time to read information sheet if participant hasn’t already.
2.) Obtain consent
3.) Reiterate the key elements of information sheet

Thank you for agreeing to help us with our study. Please ensure that you have read and understood the participant information sheet and signed your consent form. Please remember that only the researchers will know what you have written.

You can say as much or as little as you like.

Most importantly – Please remember that there are NO right or wrong answers to the questions. What we are most interested in is your experiences and opinions.

Please try to answer each question as fully as possible.

a) What do you think are the important aspects of managing T2D?

(Prompt: How important is the Diagnosis stage? How do patients adapt to living with T2D?)

b) What do you understand by the term self-management?

c) Do you think patient self-management is important?

d) Do you apply the concept of self-management in day to day consultations and if so, in what ways?

(Prompt: How? How do people respond?)

e) What help and support do you give to patients when they are diagnosed with Type 2 Diabetes?

(Prompt: What needs do they have? How do people respond?)

f) What challenges do you think patients face in getting used to living with Type 2 Diabetes?

g) Do you think there are benefits in 'self-managing' for the patient/service user?
(Provide examples if you like)

h) Do you think any shortfalls of the self-management approach for the service user?

(Provide examples if you like)

i) What barriers and enablers are there to managing T2D?

j) How does empowerment inform your day-to-day work and approach to patient self-management?

k) What are the barriers to and opportunities for empowering patients to self-manage as a health professional?

l) What do you consider to be successful T2D ‘self-management’?

m) What do you consider to be unsuccessful T2D ‘self-management’?

n) Has the empowered self-management approach changed the way that you work and your relationship with patients? If so, how? If not, why?

o) What training and support needs in practising empowerment and encouraging self-management?

p) Is there anything you think I should have asked you which I haven’t?

Do you wish to be contacted at a later date for a feedback session about the research and we will send you an invitation through the post? yes / no (circle)

Thank you for your participation.
### Table 10: Research questions with pathway to corresponding data collection tool question number (and comparable questions).

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Un/Successful management (RQ 1)</th>
<th>Barriers/Enablers (RQ2)</th>
<th>Similarities and differences HCPs &amp; patients (RQ3) (comparable questions)</th>
<th>T2D process-related questions &amp; additional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient focus group topic guide</td>
<td>Covered in Question/s: e, f, g, h, i, k, l, m &amp; n</td>
<td>Covered in Question/s: c, e, f, h, i &amp; j</td>
<td>Covered in Question/s: e, h, j, k m, n &amp; o,</td>
<td>Covered in Question/s: a, b, c, d g, o, p, q r &amp; s</td>
</tr>
<tr>
<td>Patient one-to-one interview</td>
<td>Covered in Question/s: e, f, g, h, i, k, l, m &amp; n</td>
<td>Covered in Question/s: c, e, f, h, i &amp; j</td>
<td>Covered in Question/s: e, h, j, k m, n &amp; o</td>
<td>Covered in Question/s: a, b, c, d g, o, p, q r, s &amp; t</td>
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<tr>
<td>Section 1:</td>
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<td>Section 2:</td>
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<td>h</td>
<td>Passim (process)</td>
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<td>Section 3:</td>
<td>k, l, m &amp; n</td>
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<td>j, k m, n &amp; o</td>
<td>Passim (process)</td>
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<td>Section 4:</td>
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<td>p &amp; q (information)</td>
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<td>Section 5:</td>
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<td>s, t &amp; u (open)</td>
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<tr>
<td>Healthcare professional one-to-one interview</td>
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Appendix Three: Published articles in peer-reviewed journals


Information seeking and use amongst people living with type 2 diabetes: an information continuum

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The purpose of this study was to examine the motives that people with type 2 diabetes (T2D) have in seeking information about their condition, and how information is used in self-care. Semi-structured interviews (N = 25), focus groups (3 × N = 12 participants) and open-ended questionnaires (N = 6) were used to collect qualitative data. Data were analysed thematically using framework analysis. In total, 37 participants took part, all recruited from a community-based diabetes participation group. The majority of respondents were older people (aged 60+) living in a socioeconomically deprived area. Information seeking is usually preceded by different types of uncertainty. Patients’ motives for information seeking varied, and included (1) only when necessary, (2) for reference, (3) to gain an understanding of ‘changes to their body’, (4) to gain understanding of biomedical information and research and (5) to establish entitlement to health services and service quality. These motives influenced the information sought, and how the information was applied in diabetes self-care efforts. The types of information sought also corresponded to patients’ socioeconomic status, educational level and distance from diagnosis. The findings suggest that information-seeking behaviour is differentiated — a priori — by the type of information sought. This process is informed by experiential knowledge and access to social resources. The data also suggest that socio-contextual issues are a strong influence on how information is sought and applied by those self-managing T2D, and that this needs to be taken into account in the provision of information to patients.

Keywords: type 2 diabetes; health information seeking; health information provision; use of health information; qualitative; self-care

Introduction

The production and promotion of health information is widespread across all sectors of health and healthcare, and is an important area of health policy and practice (Dixon-Woods 1998, Picker Institute 2006). Information use is, undoubtedly, a central part of healthcare management, particularly in long-term conditions where the majority of day-to-day treatment and care is self-managed (Picker Institute 2006, Powell et al. 2007). The aim of this study was to examine the motives that people with type 2 diabetes (T2D) have in seeking information on their condition, and how information is used when self-managing T2D.

T2D in a chronic condition, requiring lifestyle changes, such as dietary changes and increases in physical activity, as well as medication-taking, to control it and avoid

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ISSN 1466-3320 print ISSN 2164-9555 online
© 2012 Institute of Health Promotion and Education
http://dx.doi.org/10.1080/14663320.2012.665581
http://www.rytdh.org.uk
life-threatening complications. The illness is self-managed with the ultimate aim to keep blood glucose levels within set targets. There is some evidence for an association between health literacy and glycaemic outcomes in T2D research – with better outcomes being apparent for those most able to understand and use the information that they are given (Powell et al. 2007, Osborn et al. 2010). In terms of seeking information, studies show that the process is mediated by how appropriate the information is to the concerns of the person living with T2D, with people tending to seek information that reflects their current needs (Ouwedine et al. 2011). There is also evidence of variation in how actively people seek information (Longo et al. 2010). Other studies (Powell et al. 2007) have found an association between poor glycaemic control and low health literacy. These findings suggest a range of mediating factors, which influence the ability of the patient to apply health information for managing diabetes.

Studies relating to the application of health information have found that information is acted on and enhanced where the individual is able to draw on social support (Osborn et al. 2010) and healthcare professionals (HCPs) to interpret more complex information (Longo et al. 2010). Key factors found to mitigate the ability to act on T2D-related health information include poor general literacy (Longo et al. 2010), lack of awareness of target blood glucose and blood pressure management and finding diabetes-related health information confusing (Ouwedine et al. 2011). Whilst there has been some work examining factors that may predict how information is used in general (Longo et al. 2010, Ouwedine et al. 2011), there is no work exploring the precise motives of people with T2D in seeking information about their illness as self-reported by patients themselves rather than inferred from the HCP perspective. This study examined patient motives for information seeking amongst people with T2D. This study also explored the ways in which this health information is used to inform self-management of T2D, and factors that mitigate how health information is sought and used. This paper explores the ways in which information is used by people with T2D and suggests that information is sought and used in different ways, and for different reasons, by individuals living with T2D.

Methods
Participants were recruited from a Diabetes Patients and Public Involvement Group, a support group for people living with T2D, in an inner London borough. Qualitative data were collected using a mixed-method of data collection to maximise participation in the study. Thirty-seven (N = 37) participants took part through semi-structured in-depth interviews (N = 25), three focus groups (N = 12 people) and open-ended questionnaires (N = 6) – with some participants taking part in both focus groups and interviews. All the respondents were asked about the types of information they sought in relation to their condition, how they accessed it, why they sought information, as well as how they used it. Demographic data, such as age, gender, marital status, ethnicity, educational qualifications and household income, were collected from participants using a questionnaire. All data were transcribed verbatim and thematically analysed using framework analysis (Richie and Lewis 2006).

Results
The findings presented here are split into four parts. The first section briefly outlines the socio-demographic characteristics of the sample captured. The second section describes
the key sources of information on T2D identified by respondents, followed by a focus on
the triggers to seeking information reported by participants. The third section explores the
different styles of information seeking exhibited by this sample. Finally, these results are
contextualised in the fourth section, where socioeconomic and other contextual factors are
presented in an attempt to further explain the patterns of behaviour observed.

Sample profile
The majority of respondents (86%, N = 32) were aged 60 and over reflecting the increased
incidence of T2D amongst older people, 65% (N = 24) of respondents self-reported as
white and 35% as black. Only N = 6 (16%) respondents were living in a household with
an above average household income, and those with higher household incomes were the
only respondents educated to degree level or higher. In contrast, N = 7 (22%) of
respondents lived in households with an income which fell below £8000 p.a. (half of the
UK national income average) and these respondents were most likely to have education to
Primary School level only. The majority of respondents were educated to Secondary
School level (51%, N = 19).

Sources of information and triggers to information seeking
Respondents reported accessing information from a variety of sources, with the Internet,
pamphlets, books, diabetes groups and HCPs being the most frequently reported sources.
Respondents were asked their reasons for seeking information and were asked to provide
examples. Information seeking was usually triggered by one of the three types of
uncertainty. These are outlined below.

Symptom uncertainty
The first trigger for information seeking was symptom uncertainty. Respondents spoke of
experiencing symptoms and needing to discover the cause of the symptoms. Uncertainty
occurred where it was possible for respondents to ascribe the symptoms experienced to
another illness, or where respondents did not actually know whether their experiences
constituted clear diabetes symptoms — thus prompting people to seek information and
clarification of their experiences.

I knew I was ill but it wasn’t what I associated with diabetes and I should have recognised it —
but I just thought it was a type of flu. (Interview respondent #10 — p. 1; Line #: 20).
It was not until information was sought that the non-descript symptoms experienced by
this participant were identified as having a more serious cause.

Response uncertainty
The second trigger for information seeking was where a sign or symptom of illness had
been experienced and recognised as such, but where people were unsure about the
seriousness of the symptom, and whether the symptom warranted medical intervention or
could be dealt with through self-management.

I am sweating a lot and they say you’re supposed to let them know any little thing that has
changed, and I haven’t been to see them [doctor] just looked on the Internet to see. But you
still don’t know. But then you could go and it’s fine. But then they say it’s better for you to be
sure. But I’m just ... I don’t know, maybe it’s just me. (Interview respondent #9 — p. 8;
Line #: 40).
This quote exemplifies the reasoning behind information seeking. In this instance, the participant wants to find out possible causes for the symptom experienced and also experiences uncertainty about whether or not to seek medical care, or respond by self-managing the symptoms.

**Information uncertainty**

The final trigger for information seeking emerged where participants sought clarification or further information on top of that already accumulated. This was usually where existing information did not reflect the patient experiences or understanding, or where information has changed rapidly with new developments in treatments. Information uncertainty also emerged where there was contradictory advice, from different professionals and/or other sources of information such as that found on the Internet.

They tell you one thing one day, and another thing another. (Patient interview respondent #9 – p. 3; Line #: 13).

In this case, information was sought from alternative sources to clarify confused messages.

**Styles of information seeking**

Once participants had decided they required information to address their uncertainty, the approaches taken to find information varied. Five styles of information seeking were identified within the sample and these are presented here.

**Didactic information**

At the most basic level, didactic information was collected simply to provide a baseline of knowledge about T2D and management of the condition, upon which future decisions and behaviour could be based. Minimal use was made of this information beyond a basic understanding of the disease.

I pick up the leaflets, I’ve read them, I know them almost back to front. I know what I should do and what I shouldn’t do. (Interview respondent #6 – p. 9; Line #: 25).

This quote illustrates this basic type of information use. No further information was sought, and there was no expectation that any additional information needed to be actively sought at a future time.

**Reference**

Moving on from baseline information, some participants collected information either for reference, or to inform their response to future events or symptom change.

If it is needed I use it, if it is not needed I’ve got a box with all the information in it so I can refer to it if necessary. If I get a cold for instance I will look up to see what I should be doing or shouldn’t be doing and I find them very useful. It is a box about so big, a big file and I keep it with me in the house and I refer to it if I need to. (Interview respondent #4 – p. 3; Line #: 21).

This information was not applied preemptively to inform day-to-day responses but rather, stored, against future needs.
Active self-management information

One grouping of respondents also described actively seeking out information to enable them to better self-manage their condition. Here, information was used both as a tool for planning disease and symptom responses, as well as for planning prevention strategies.

I get lots of information explaining everything to us. Things like, even a tin of baked beans has sugar in it so you need to consider that. It is very good, and goes into the details of what has caused it, and what the symptoms are and what you can do to stop your sugar going up. (Focus group 3 respondent 2 – p. 14; Line #: 39).

The information here is digested and acted upon rather than simply stored. The participant uses the seemingly small piece of information about food labelling to relate it to how such information can help with their understanding of the disease as a whole. So the information is assimilated within the person’s overall understanding of the disease.

Information use to increase clinical options

The fourth style of information seeking involved a move beyond enhancing self-management in the home, towards the development of a clinical knowledge base to enhance the self-directive capacity of participants in relation to the array of clinical options open to them. This is illustrated in the following quote, where the respondent is aware of the need to keep his knowledge base continually updated not only to inform his own self-management of the disease, but also to ensure that the medical professionals involved in their care are also ‘up to speed.’

All medicine is forever changing and what’s believed at one point can be overturned by new research and if you don’t know about it, you will carry on in the same old way perhaps creating problems, and you can’t assume what’s good for one is good for another. It’s a juggling act. [...] You need to keep your knowledge up to date. If your knowledge is stuck at some point in the past you can’t assume that your doctor is up to speed, you just can’t. You need to know what’s available, and how it could benefit you. (Patient interview respondent #7 (m) – p. 7; Line #: 34).

Information is used here both as an individual tool and as a way of informing others. The participant here has not only stored and assimilated, but has also accommodated the information in the general schema of their knowledge concerning illness in general.

Information use to improve quality of care

At its most sophisticated level, information was actively sought and used in a multitude of ways with the aim of improving the quality of care provided by others and the capacity to self-care. At this level information seeking was both self-directive and assertive.

The cleverest person in the world can always learn something, I’m not one of those people who says I know it all therefore I don’t need to look any more. I am not like the doctor with the bit of paper who says I’ve learned it. Well new things come along. [...] The National Health Service are very good at foisting you off – but when you say this is what I want, and this is what I’m entitled to they always back down, always. (Interview respondent #10 – p. 3; Line #: 21).

This quote illustrates how information was used not just to ensure that appropriate and up-to-date care was received, but that this care was of the highest quality. The person here has not just stored, assimilated and accommodated information about diabetes per se. They have digested the information and linked it with knowledge relating to successful health system use. As such, the information here is used actively, purposefully and in the context
of the options that are available to them through the system in which decision-making surrounding the illness is made.

**Contextualising information use**

Information is clearly important, but simply providing information in a uniform manner is not sufficient for all recipients. There can be little doubt that those who use information in the most sophisticated ways are likely to get the most from the information, and the most from those providing care. To explore this further, we looked at the demographic characteristics of the sample to contextualise the styles of information seeking identified above.

When we analysed the background information gathered in relation to styles of information seeking, income and education were found to be key features. People seeking didactic information and using information minimally were all on the lowest incomes. In contrast, those seeking to 'improve quality of care' were a similar age but had the highest incomes, the highest levels of educational attainment and professional backgrounds.

In addition, distance from diagnosis was a key factor in shaping how information was used. Respondents were more likely to use information in more sophisticated ways after they had lived with the disease for three or more years. Most of those seeking didactic information were within a year of diagnosis, which may explain the need to collect baseline information and the inability to move beyond this stage, as initial information is digested. When asked why they sought information, didactic information seekers focused on a desire to reduce the occurrence of symptoms whilst reference seekers tended to seek to minimise disruption to day-to-day life and family life through routine. Self-management information seekers came closest to the shared decision-making model promoted by diabetes HCPs as the ideal model of care — however information sought by these participants was often used to ensure continuity of care — by being able to report their understanding consistently to different HCPs. Many of this group had lived with T2D for three or more years, but had lower incomes and educational attainment.

The effect of time, experience and social resources on information seeking suggests that styles of information seeking can be seen as a sequential (gradually adopted) continuum, with the factors inhibiting or enhancing how far along the continuum a person is able to move. Hence, the five styles of information seeking can also be placed on a continuum, with one stage building on the other and social resource strongly influencing how far along the continuum a person was able to go (see Figure 1).

**Conclusions**

The results of this study suggest that both information seeking and the use of information are affected by the social resources available to people living with diabetes. Those with the most resources were able to accumulate and use information effectively; thus, participants with higher socioeconomic status and higher levels of educational attainment were more likely to seek and use information to improve the quality of care received. This suggests that the current focus on individual capacity and preferences in relation to information seeking and use in T2D is insufficient if the aim is to enable, inform and empower patients. The wider social context in which the person with diabetes is living, as well as the social resources available to them, is also crucial to ensuring effective and high quality care.

In addition to, or in combination with, social context, the length of time that an individual has been living with T2D is also an important mitigating factor. The type of
uncertainty experienced, and the information required by different patients – at different stages of the illness career – also needs to be considered as part of the information giving process. Thus, information needs are individual, socially contextual and temporal in nature. In practice, whilst adopting this multi-layered approach to information provision makes the processes around the provision of information more complex, it should enable HCPs to tailor information more specifically to the needs of each patient at each stage of their journey, and also enable them to better support patients in effectively using the information that they are given.

The findings of this study enhance previous research suggesting that people living with T2D tend to seek information for their current needs (Longo et al. 2010), by demonstrating that patients’ baseline understanding and social resources orientate the type of information sought, and how it is applied. The present findings also suggest that health information provision should reflect and address the sources of the patient uncertainty, motives for seeking information and be able to provide information-seeking strategies relevant to the patient’s current circumstances to ensure that relevant information is sought and applied by the patient in the most appropriate and effective way.

One limitation of this study was that it was unclear whether the different styles of information seeking and use were related to different sources of information (Internet, leaflets, support group members, etc.) – as nearly all respondents reported having access to similar sources of information. Further research may be required to clarify the degree to which the type of information available is an influencing factor in information seeking and use.
Acknowledgements
We thank King’s College London for sponsoring this study and also the participants who were involved in this study.

References
Marrying contradictions: Healthcare professionals perceptions of empowerment in the care of people with Type 2 Diabetes

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\textbf{ARTICLE INFO}

Article history:
Received 20 July 2010
Revised in revised form 16 March 2011
Accepted 26 March 2011

Keywords:
Type 2 Diabetes
Empowerment
Healthcare professionals

\textbf{ABSTRACT}

Objective: The aim of the study was to establish how healthcare professionals (HCPs) involved in Type 2 Diabetes (T2D) perceive patient-empowerment. We aimed to identify their understanding of empowerment, and how these inform their day-to-day practice.

Methods: Employing a qualitative approach, ten interviews with diabetes HCPs in two local Health Trusts were conducted. Data were transcribed verbatim and analysed using framework analysis.

Results: HCPs viewed empowerment as a rejection of the paternalistic approach. Emphasis was given to ways of balancing clinical aims against patients' concerns. Some saw the approach as improving service quality, whereas others saw empowerment as a process of social justice. These were related variability to the expedient use of resources.

Conclusion: Models of empowerment, which promote that HCPs bring clinical expertise and patients' 'lay' expertise of illness to the medical encounter, are inadequately descriptive of how empowerment approaches are actually engaged with, by HCPs.

Practice implications: The empowerment approach is construed and utilised in different ways. Clarification of what empowerment entails in practice for HCPs, as well as what HCPs perceive are its multiple aims, is required.

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1. Introduction

Type 2 Diabetes (T2D) represents a long-term condition where the ability to respond to the effects of the condition, through diet and lifestyle change as well as medication-taking, can be crucial to improved health outcomes [1,2]. In recent years, a key health-education philosophy informing T2D care has been the empowerment model [3,9]. The model is far from new; the origins of empowerment go back to the work of Freire who argued that empowerment is about action that leads to liberation and which is generated by the person's perception of the power dynamics that operate in their lives and the ways in which they can or cannot change these dynamics [5]. The empowerment model asserts that an equipoise relationship in traditionally healthcare professional (HCP)-led care is possible. This relationship occurs where professionals' clinical and bio-medical expertise and patients' lay expertise of managing diabetes converge. As such, the model is primarily about patients' gaining of power embedded in social interaction [5]. Empowerment is defined as \textasciitilde...[a] process whereby patients have the knowledge, skills, attitudes and self-awareness necessary to influence their own behaviour and that of others in order to improve the quality of their lives\textasciitilde [4] (p. 38). Professionals' understanding of the empowerment approach is important as it influences how the HCP actually practices empowerment. The present study employed qualitative semi-structured interviews with HCPs working in T2D care. In carrying out these interviews, the present study wished to explore how HCPs' understanding of empowerment influences their practice of empowerment in day-to-day clinical work. In this sense, the HCPs' 'practice of empowerment' refers to how a HCP addresses patient concerns using the HCP's understanding of what empowerment entails.

Therefore, one overarching aim of the present study was to establish how professionals use empowerment policies, and to explore and critically appraise how empowerment is employed in day-to-day clinical practice.

This aim was translated into three specific research questions:

- What are HCPs' personal understanding of what empowerment means?
- Do professionals feel the empowerment of patients is important and if so why?

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Do HCPs feel that current health policy, their institution or working environment have any effect on their ability to practice in an empowering fashion?

2. Methods

The study adopted a qualitative approach to engage with professionals associated with diabetes care. Respondents were recruited from a London Acute and Primary Care Trust (PCT) for a single health-catchment locality. HCPs were snowball-sampled, starting with a Patient Involvement Officer at the PCT. Each professional interviewee was asked to recommend another professional who they felt may have a pertinent strategic role, e.g., diabetes nurse specialists, community podiatry leads, consultant diabetologist. A small \( N = 10 \) sample of experienced practitioners occupying strategic positions in terms of policy application and patient contact – hence yielding a greater depth to the data – was used. Using a relatively small sample of participants in research in healthcare settings, can be a useful, efficient, practical and yet still ensure valid and meaningful results [10–13].

The research was granted ethical approval by the local hospital’s Research Ethics Committee. Each research question was addressed in the study by asking HCPs, wherever possible, to illustrate their conceptual understanding with examples from their day-to-day work. Data collected over the period of April–June 2007, were transcribed verbatim and were analysed using framework analysis. Framework analysis is a popular and well-justified method of qualitative analysis in health-related studies [8]. The approach included the adoption of systematic and visible stages to the analysis process, as well as independent coding by two of the researchers. Both researchers developed key themes from the data and systematically checked that emerging categories were consistent, by negotiating the content, as well as the expansion and development of emergent themes. In developing and applying the framework for analysis, researchers drew from current debates on the definition of empowerment. As the Authors’ own works in this area were included, epistemological reflexive monitoring was employed to reduce bias in analysis [17].

3. Results

The use of empowerment by professionals was discussed in the professionals’ responses to their understanding of empowerment, and why they felt empowerment was important. Four key synthesized themes emerged, relating to:

1. The graduated rejection of ‘paternalism’.
2. Empowerment as employing a new patient-professional ethos.
3. Empowerment as balancing clinical aims against patients’ personal concerns.
4. Empowerment as an expedient use of resources.

A description of these themes appears here and a detailed discussion of how these answer the study research questions follows in Section 4.1.

3.1. The graduated rejection of paternalism

All respondents (Rs) stated clearly that the ‘days’ of paternalism could not be returned to. However, respondents differed in the degree to which they rejected paternalism:

"I think in the old days we used to go in with a checklist—OK, they’ve done this and we’d tick off all these things and say ‘I’ve taught them [patients] about this’ […] and go down the list ticking them [metabolic targets] all off … It doesn’t work that way. Not if they feel they need to do it for someone else.” (R #6).

Others were more flexible acknowledging that patients brought their understanding to the encounter and participated (or not) in their own terms. Other professionals believed that paternalism could be used to ‘activate’ self-management by ‘weaning’ the patient away from directive care (and gradually introducing self-management tasks), as well as keep the door of negotiation open.

"I do have to assess how much information people want. So there is no point in bombarding people with information if they say ‘That’s great Doc, tell me what to do’.” (R #9).

The attainment of clinically driven targets through paternalism was seen by some as the first step in assisting people to improve well-being. This, the HCPs interviewed believed, created a baseline from which to develop more empowering practices. Other respondents wished to distance themselves from the ‘heroic medicine’ worldview where HCPs know best and thus are there to save lives, arguing professionals should merely facilitate and support the patient’s ability to respond to their illness. ‘Ownership’ of the management of T2D by patients was seen by some as a prerequisite to successfully managing the illness.

"… essentially if you have a chronic condition you’re the only person living with it 24/7. So you become the expert … as far as I’m concerned, the person with diabetes is the expert on their diabetes, their job, their family. And I’m there to support them [patients] in whichever way they feel they want for in managing that condition.” (R #8).

However, it was also acknowledged that factors such as advances in pharmacology and psychosocial education tools contributed to empowerment.

"[G]sometimes you can tailor things. … We have more flexibility. … For example, with shift work I will prescribe drugs that will avoid making their sugars go low because we have so much choice now.” (R #7).

3.2. Empowerment as informing a new patient-professional ethos

The shift away from paternalism was reported to have impacted upon face-to-face encounters as well as wider approaches to the position of the patient in healthcare. Acknowledging patient experiences and expertise was seen by professionals as contributing to the quality of the outcomes at the patient and professional interface, as well as redressing power relations. Some saw this as a process of democratic renewal relating to social justice, and giving patients a voice.

"… [I]f you don’t empower the users of services, and the community in its wider context, then you could argue that those services are poorer and not so relevant. But particularly in health, given that we have a statutory responsibility to involve patients in the last couple of years, then I think it’s an area that needs developing further, and really to a certain extent, our democracy. If we live in a democratic society then our services should be within that spectrum.” (R #9).

Many others, however, focused on the contested idea that there is evidence for the educational model underpinning the empowerment approach.

"So I guess that’s why they like it as well [is] because in the majority of people it is effective, you know, it’s an effective way of managing their diabetes … there is evidence it works.” (R #6).
Nevertheless, drawbacks were also reported, where professionals encountered knowledgeable and assertive patients:

"Quite often people …… who don’t wish to comply with say, for instance, set QOF targets which we’re trying to meet. They are able to become expert patients and then justify to me why they don’t wish to comply. So it really gives them [patients] the ammunition to say I am well informed, I am an expert, and I don’t want to take blood pressure pills because they make me feel ill and I’d far rather accept the risk which you’re so clearly explained to me ….. And I think you cannot ignore the dilemma that health care professionals are put in where you’ve got to get your QOF targets, which are completely based on metabolic targets and it’s how we’re performance managed, and at the same time you’re encouraged to push people to self-manage and give them [patients] the power to decide about what their control will look like, and the two don’t match up.” (R#10)

This contradiction caused dilemmas for professionals where empowered patients challenged the biomedical target-focused system, raising concerns about the match between policy and practice and the potential for intolerant, sick-role empowerment. In summary, empowerment was seen by HCPs as an activator to behaviour change, improving quality of care in isolation, or in conjunction with more directive approaches.

3.3. Empowerment as balancing clinical aims against patient concerns

Respondents described how, in day-to-day practice, empowerment involved balancing their clinical aims against what the patient viewed as quality of life. That the patient was willing or able to do to meet their needs, or merely the patient’s capacity to respond.

"It’s crucial you assign importance to the patient …… the bottom line is keep the diabetes well controlled by adapting it to what they feel they can do.” (R#7).

Professionals also reported that empowerment was a process of 'skilling' patients to tend and respond to their diabetes. Many saw these skills as crucial to patient well-being, as the skills emerged when patients acknowledged that it was their illness, and professionals accepted their role as a facilitator and source of health information.

"I think it has altered the way I practice, and I think I’m very much, I accept now that the diabetes is the person’s diabetes, not my diabetes and my role is very much to support them [patients]” (R#9).

Many viewed empowerment as an acknowledgement of skills previously marginalized, or unrecognized, in their profession (i.e., they had ‘always worked that way’), in particular nurses. There were also differing views on the suitability of self-management in relation to other ‘empowerment initiatives’, such as patient-led service development.

3.4. Empowerment as an expedient use of resources

This theme had three key elements. First, it was argued that epidemiological change and the growth of chronic illnesses meant that the patient role had changed from passive to self-regulatory, and as such, support and education were most appropriate.

"I think that … particularly diabetes …… you have to have patient involvement because it’s not like if you had a pneumonia, you were unwell for a six week cycle, convalesced and got over it …… But with diabetes if you have it, you have it. So the whole process of managing had to be: I think, strongly led for the individual - but within a supportive structured framework because they can’t do it on their own.” (R#7).

Secondly, it was argued that there are finite resources available for health and that patients need to pick up ‘some of the slack’ (R#1). Targeting the patient was also seen as efficient, responsive to need and cost-effective:

"I think that unless we ask the opinions of the people who are going to use this service there is absolutely no way of knowing that we can meet her needs.” (R#1).

Relating to this, it was seen that improving the quality of the patient experience improved the reported quality of services provided.

“They [patients] make sure that we are keeping up standards and developing services that are appropriate for our community ….. they have choices about going elsewhere. So I think they drive quality from many different levels.” (R#7).

4. Discussion and conclusion

4.1. Discussion

A limitation of the study is the small sample, which although it offers depth to the issue of HCP perceptions of empowerment, it might limit the extent to which our findings can be generalized. Another limitation is the setting, as the organizational and policy-related issues are unique to the UK National Health Service, although many of the aspects relating to the understanding of the philosophy of empowerment may resonate with other countries. As such, these findings need replication with larger samples and different healthcare systems before they are generalized.

What is apparent in practice, however, is that the empowerment approach is understood and enacted in a variety of ways. In terms of HCP understanding, empowerment is seen as a new way of managing illness, overcoming the shortcomings of paternalism and focusing on involvement of the patient in self care. Empowerment in our sample was used flexibly, however, and readily suspended by HCPs to reflect patient preference. It was also seen as a gradual process meaning the patient away from paternalistic consultation styles from a directive baseline ensuring blood sugars are stabilized before encouraging self-care. Thus, empowerment was seen to be flexible according to the patient, illness progression and circumstance. Our work is hence in line with work by Lutwy [6] who showed that professionals adopt the positions of “educators, detectives, negotiators, salesmen, cheerleaders and policemen …[i]o … tailor their actions to specific patients in order to maximise their adherence to treatment regimens”[p. 421]. Similarly, a range of, often contradictory, meanings were attributed to the concept. One of the reasons behind this lack of clarity as to what empowerment actually means in practice, could be the great similarity between this concept and a related one, that of patient-centredness [13]. Recent work [14,15], moves us closer to identifying commonalities and contradictions between the two.

When asked why empowerment is important, HCPs emphasized the flexibility of the concept. HCPs who rejected paternalism saw empowerment as an educational model for skilling patients to act and emphasized that consulting people meant public resources were targeted to people's actual needs. Those who saw paternalism solely as being over-directive with patients, however, saw empowerment as a process of activating patients to self-care and share risks so clinical approaches could be tailored to their
concerns. In the UK, the patient-centric elements of the empowerment philosophy have been extended throughout the NHS within and beyond the realm of T2D care management. Criticism of the approach [13–15] suggests that the meaning of empowerment needs to be explored with a mix of HCPs as little is known about empowerment in practice. The present study supports the conclusions of recent work [13] appearing in this journal, proposing that “although empowerment pervades NHS health policy, it is ill-defined in this context” (p. 176). For HCPs in the present study their professional understanding of empowerment needed to tally with their wider understanding of the needs of the health service. So, the work presented here suggests more heterogeneity in HCPs’ views of empowerment both in ethos and the outcomes than they wish to achieve. Malterud [18] has suggested two types of empowerment: ‘strong empowerment’ relating to an emancipatory-based challenge of power inequalities in health. The second type is ‘educational empowerment’ where HCPs are seen to merely encourage patients in the taking up of health-promoting behaviours, rather than anything more substantial. The present study confirms one aspect of Malterud’s observations, that much of the emancipatory empowerment ethos has faded in application, in favour of ‘educational’ empowerment. HCPs are inspired by the ideas that originally gave rise to ‘strong’ empowerment, but at the same time are constrained by the context in which they function and in which they are evaluated, and end up using empowerment simply as a tool to health promotion or for improving the quality of services.

Finally, the present study suggests that in practice HCPs work within the wider contextual constraints and enables of policy and the needs of the populations they serve. These factors affect how empowerment is enacted by HCPs. In previous studies, the ability to enter an equipotence relationship has been questioned as HCPs and wider regulation produce the choice and resource array offered to patients [7, 16]. It was found here that the performance-related targets which HCPs are measured by are not necessarily compatible with patients’ views. So, where HCPs are encouraged by policy to follow the empowerment agenda and support patient choice, their success in doing so is evaluated by biocultural targets that the empowered, choice-exercising patient may have decided to reject, rendering the translation of the empowerment agenda into practice, difficult. This means that there are contradictions inherent in the practice of the empowerment approach are not just theoretical problems, but practical ones faced by HCPs in their day-to-day work.

4.2. Conclusion

HCPs appear to carry contradictory elements of the empowerment approach by drawing from the disparate aspects of the empowerment approach in a way that meets their personal understanding and professional values, patient preference, and wider contextual issues impacting on their practices.

4.3. Practice implications

The present study is one of only few that have attempted to understand what empowerment means in practice from a HCP rather than a patient perspective. It suggests that HCPs have an understanding of various components of the concept of empowerment but the application of the concept in clinical practice is not seamless. For example, whilst HCPs are asked to encourage patient choice, at the same time they have their practice evaluated by biocultural targets that may have been rejected by patients who have exercised their right to choose. Also, HCPs draw on disparate aspects of the empowerment philosophy to make the concept fit within the constraints acting upon their day-to-day practice. Not only do these contextual constraints, which are predominantly rooted in health policy, need to be addressed. But also, further clarification of what empowerment entails in practice is required if empowerment is to move from being just another approach to improve ‘adherence’ and service quality, towards being an approach concerned with actually addressing psychosocial issues.

References