Barriers to self-management in type II diabetes

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Abstract

Thesis title: Barriers to self-management in type II diabetes. Conducted at The University of Manchester by Emily Bland for the award of Master of Philosophy (MPhil)

Research questions: The primary research question is to identify barriers to self-management for people with diabetes in type II diabetes. The secondary research question is to assess the effectiveness of the normalisation process theory when looking at how individuals implement practices in their everyday lives.

Background: Type II diabetes is both a worldwide and national healthcare. Certain self-management practices can help people with diabetes to control the condition, these include dietary changes, increasing physical exercise and adhering to a medication regime. However, not all people with diabetes are undertaking these practices. A literature review identified gaps in the literature reviewed relating to social processes and contextual barriers. The normalisation process theory: To address these gaps the normalisation process theory was used to develop interview questions and analyse data.

Methods: This study was nested in a National Institute for Health Research funded Collaboration for Leadership in Applied Health Research and Care (CLAHRC) study. Twenty six participants from the CLAHRC study were interviewed in Greater Manchester and the surrounding area. Data were analysed employing the framework analysis approach, using a framework devised from the normalisation process theory.

Results: The results of this study supported and expanded on the findings of the literature review. New contextual, social and individual barriers came to light. The use of the normalisation process theory was both a strength and a weakness of the study. Using the theory sensitised the analysis to social and contextual barriers, but barriers relating to individual differences did not sit well in the theory.

Conclusions and Contribution of Research: Supports previous evidence of the importance social networks, expanding by identifying that this work is not recognised. Identifies barriers associated with the urban environment and employment. There is tension between quality of life and self-management for participants. Contributed to the knowledge about how people understand diabetes and how that understanding affects self-management. To be able to apply the normalisation process theory more effectively to individuals, work should focus on using it in conjunction with the theory of planned behaviour.
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I dedicate this thesis to my nana

Introduction

1.1 Aims

- The primary aim of this thesis is to identify barriers to self-management for people with type II diabetes.
- The secondary aim is to assess how useful the normalisation process theory can be when applied to individuals operating in open systems.

1.2 Research Questions

- What barriers do a sample of people living in Greater Manchester experience to implementation of self-management practices?
- Does the normalisation process theory describe the process by which self-management practices are implemented by individuals?

1.3 Background

Type II diabetes is a growing public health concern (DOH, 2005). In 2011 type II diabetes cost the NHS approximately £8.8bn, this figure is only set to increase (Hex et al, 2012). Type II diabetes is characterised by insulin resistance, insulin being the hormone which controls blood sugar, and loss of β-cell function, resulting in elevated blood sugar (Wass and Stewart, 2011; Zimmet and Alberti, 2004). This is monitored with a blood test known as an HbA1c test, ideally people with diabetes should have an HbA1c level of below 6.5% (48 mmol/mol) for most people with diabetes and below 7.5% (58 mmol/mol) for those at severe risk of hypoglycaemia (Diabetes UK http://www.diabetes.org.uk/Guide-to-diabetes/Monitoring/Testing/; Rodbard et al, 2009). These levels are open to negotiation between the individual patient and their doctor (NICE, 2009). If hyperglycaemia continues there is a risk of complications from the condition, these include retinopathy, neuropathy, and nephropathy causing blindness, loss of limbs and renal failure respectively, at worst diabetes can result in heart attack or stroke and loss of life (Nussey and Whitehead, 2001; Wass and Stewart, 2011).

1.3 Risk factors for type II diabetes
The aetiology of type II diabetes is complicated, involving several risk factors. These include genetics, obesity, physical inactivity, ethnicity, and lower socioeconomic status in developed countries (Wass and Stewart, 2011). Those of South Asian, Middle Eastern, African, Polynesian and Hispanic descent and the indigenous people of Australasia and America have a greater risk of developing diabetes than European populations (Wass and Stewart, 2011)

1.5 Management of type II diabetes

Diabetes can be controlled medically either through oral medication or insulin which is injected (Rodbard et al, 2009). Alongside medical treatment, people with type II diabetes can undertake a range of self-management practices with the aim to improve glycaemic control. These practices include dietary changes associated with diabetes, undertaking exercise, taking medications, attending medical appointments, monitoring the condition such as through the use of blood sugar monitors or foot care. Together these practices can be collectively termed self-management (Funnell et al, 2011)

Type II diabetes and self-management of the condition are addressed further in chapter two, which outlines the background to this study in greater depth.

1.6 Study background

This study was nested in a wider Collaborations for Leadership in Applied Health Research and Care (CLAHRC) funded study. The aim of the CLAHRC study was to increase access to care for people with long term cardiovascular conditions with a particular emphasis on people who are socially disadvantaged (Rogers et al, 2011). The study was split into three phases: data synthesis and collection (Vassilev et al, 2011; Vassilev et al, 2013); intervention development; and evaluation. The theoretical background to the CLAHRC study is discussed in greater detail in chapter two (2.2.2). The CLAHRC study is a mixed methods

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1 **Self management**: A collection of behaviours conducted by the individual with diabetes that contribute towards maintaining blood glucose within the healthy range and thereby minimise complications. These behaviours include: controlling sugar intake, controlling weight, undertaking exercise, complying with medication regimes, attending medical appointments.
study combining questionnaire study and semi-structured interviews, the methods used for the CLAHRC study are covered in chapter five (5.2.1). The aim of this study fits into the wider study by giving deeper focus through the use of semi structured interviews.

1.7 The normalisation process theory

In an attempt to describe the implementation process and the barriers to self-management in type II diabetes the normalisation process theory (NPT) was employed to sensitise the research to these barriers. The NPT is a theory designed to explain implementation of new innovations processes in healthcare systems (May and Finch, 2009; May, 2013). Using the NPT to examine how individuals in open systems implement new practices is a novel use of the theory, therefore the second aim of this study is to assess how useful NPT is in this context. Please see chapter four for further information about the theory and how it is applied in this study.

The words “embed” and “practice” require definition to ensure accurate communication in this thesis. The Oxford English Dictionary describes embedding as “[to] implant so that it becomes ingrained within a particular context”. In this context embedding is related to the ideas and practices surrounding a particular intervention. May and Finch (2009) describe a practice as “an ensemble of beliefs, behaviours and acts that manipulate and organise objects and others”. This has been used as a working definition for this thesis.

1.8 Methods

A scoping literature review was conducted to acquaint myself with the existing knowledge and identify gaps in the literature. To manage the volume of literature examining barriers to self-management in type II diabetes, a review of reviews was performed (Smith et al, 2011). The literature included in the review focussed

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*Open system:* Describes systems where the actors in the network interact outside the network. In this case the multiple interconnected networks of an individual’s life rather than the closed network of the health service.
on individual differences, social support, and culture (see chapter three). There was scope for this study to support and expand on existing literature by examining the social processes and contextual barriers associated with implementing and embedding self-management practices. The study was not limited to social processes and contextual barriers, however, and all barriers identified were considered.

To identify barriers to self-management in type II diabetes, qualitative research methods were used to capture the experiences of people living with diabetes. The data were collected using interviews with people living in Greater Manchester and the surrounding area. Participants were selected from the CLAHRC study using maximum variation purposive sampling strategy (Patten 1990) in an attempt to capture the experiences of a variety of people. The interviews were then analysed using a framework from the NPT, employing the work of Gallacher et al (2011) and Blakeman et al (2012).

1.9 Personal background

I started this MPhil after finishing my postgraduate degree in health services research at the University of York. Before that, I studied psychology at the University of East London. I had wanted to study psychology since my early teens, finding human behaviour fascinating. I very much enjoyed my module on health psychology, but it was public health which eventually grabbed my interest. Still maintaining my interest in behaviour, I started thinking about how behaviour affected health and behaviour change interventions. During my time at York I learned a great deal, particularly about research methods and the role of health psychology in public health. I was keen to continue my education in area and was excited to start my MPhil at the University of Manchester. Before this study I had exclusively been involved in quantitative research, but I was keen to develop qualitative skills and hoped that a MPhil would be a good way to acquire these skills.

Diabetes is a condition close to me, as many people on my father’s side of my family have the condition. I have been aware of self-management since I was a small child, learning about reducing sugar intake from my paternal grandmother who had the condition. In my late teens my father was also diagnosed with the
condition, I have watched him adapt his lifestyle to manage the condition, diabetes and management has become part a big part of his life in this time. Some of these changes were things I felt I would really struggle to manage, such as avoiding sweet treats and embedding cardio exercise into his every day routine. I became interested in what motivated people to make such sweeping lifestyle changes in response to a condition which may not even be making them feel ill. This is what led me to studying barriers to self-management in type II diabetes for this study.
2 Background

2.1 Type II Diabetes

2.1.1 Classification and symptoms of diabetes

Diabetes is a condition in which the ability of the body to manage blood sugar is impaired. People with diabetes cannot process sugar from their diet and so have a raised level of glucose in the blood, called hyperglycaemia. In people without diabetes blood sugar rises rapidly after eating and then falls again. In people with diabetes this fall does not take place or takes place much more slowly and blood sugar remains high even after fasting overnight. This excess sugar can cause damage in many sites in the body. Attempts to control sugar artificially can lead to sugar falling to low and body being unable to find more from reserves, called hypoglycaemia. There are two main ways that the condition presents. In early onset, juvenile or type I diabetes the pancreas ceases to produce insulin, which causes problems regulating blood sugar. In the worst cases this can lead to hypoglycaemia, coma and stroke. The other type of diabetes known as type II or late onset diabetes, is the focus of this thesis, from this point on the word “diabetes” refers to type II diabetes. Type II diabetes occurs when the body becomes resistant to the insulin produced by the pancreas, this usually occurs in later life, around middle age, with the chances of developing type II diabetes affected by a variety of factors (Nussey and Whitehead, 2001; Wass and Stewart, 2011). The symptoms of diabetes are similar regardless of type: excessive urination, thirst, weight loss, fatigue and vision changes, although they are likely to be less marked in those with type II diabetes (WHO, 2015).

2.1.2 Global and local disease burden

In 2004, approximately 3.4 million people died globally as a result of high fasting blood sugar (WHO, 2011) and the prevalence of the condition is predicted to increase by 50% between 2011 and 2030, this rapid growth in cases means that by 2030 diabetes is predicted to be the 7th leading cause of death globally (Whiting et al, 2011; WHO, 2011).

In the UK the disease burden of diabetes is no less challenging, with approximately 3.1 million people over the age of 16 affected by the condition.
This figure is predicted to rise to 4.6 million by 2030 (Holman et al, 2011). The exact cost to the NHS is unclear, the National Audit Office estimated the burden of diabetes to the NHS to be approximately £3.9bn in 2010 but this is likely to be an understatement (DoH, 2012). A health economic analysis conducted in the following financial year reported type II diabetes to have an estimated cost to the NHS of £8.8bn and this cost is expected to increase to £15.1bn by 2035/36 (Hex et al, 2012). The financial burden of diabetes is not limited to the NHS. In the same paper, it is estimated that diabetes cost the UK £13bn in indirect costs during the same year. These indirect costs refer to productivity costs from lost work years to both inability to work and premature death as well as sick leave and the additional care required by some people with diabetes. This is a combined yearly cost to society of £28.1bn, which is predicted to rise in line with increased prevalence and inflation to £35.6bn in the year 2035/36. This financial burden accounts for approximately 10% of the total NHS budget, rising to 17% in 2035/36. Hospitalisations and complications account for much of this cost. The Department of Health estimates that 80% of the cost of diabetes is due to people developing preventable complications (DoH, 2012)

2.1.3 Risk factors for developing complications from type II diabetes

There are many risk factors for developing type II diabetes which include modifiable risk factors and unmodifiable risk factors. Modifiable risk factors include obesity (Must et al, 1999; Pi-Sunyer, 1991; Ford et al, 1997; Resnick et al, 2000, Mokdad et al, 2001 among many others), low hip to waist ratio or fat distribution (Haffner et al, 1990; Carey et al, 1996; Chan et al, 1994) and sedentary lifestyle (Grøntved and Hu, 2011; Hu et al, 2001; Hu et al, 2003). Unmodifiable risk factors include increasing age, a family history of type II diabetes (Nussey and Whitehead, 2001; Wass and Stewart, 2011), and ethnicity, with those from African, Caribbean, South Asian, and Polynesian decent and indigenous people of America and Australasia having higher risk of developing the condition (McKeigue et al, 1991; Nussey and Whitehead, 2001; Wass and Stewart, 2011). Depression (Ali et al, 2006) and schizophrenia (Dixon et al, 2000) are both risk factors for developing type II diabetes. The importance of socioeconomic status in diabetes risk is well documented, with a diagnosis of
diabetes more likely in people with lower socioeconomic status (Robbins et al, 2005; Maty et al, 2005; Evans et al, 2000; Dalstra et al, 2005; Wild et al, 2008)

2.1.4 Complications that can result from type II diabetes

Complications from type II diabetes are no less serious than those from type I. These include atherosclerosis which can lead to stroke and heart disease (Beckman, 2002; Morrish et al, 2001), retinopathy (WHO, 2015) and neuropathy (WHO, 2011). Among many outcomes neuropathy can cause loss of sensation in the legs and feet which can result in injury, tingling in the legs, loss of bladder control and loss of sexual function (Diabetes UK http://www.diabetes.org.uk/Guide-to-diabetes/Complications/Nerves_Neuropathy/). Diabetes can cause foot ulcers which can result in amputation; poor glycaemic control is the biggest risk factor for non-traumatic amputation in people with type II diabetes (Lehto, 1996). Retinopathy was present in 30% of people with diabetes screened, with 2.9% of those people with retinopathy classed as having sight threatening retinopathy (Thomas et al, 2015). Nephropathy resulting from diabetes can result in chronic kidney disease and kidney failure (Molitch, 2015). This is not an exhaustive list of the potential complications, but reflects the potential severity of the condition if uncontrolled.

These complications are more likely to arise where blood glucose (Molitch et al, 2015, Stratton et al, 2000) and hypertension (Stearne et al, 1998) is not controlled. Risk factors for complications include age and length of duration prior to and since diagnosis (Knuiman et al, 1986). Mortality resulting from cardiovascular disease in people with diabetes is inversely related to socioeconomic status, with those with lower socioeconomic status more likely to die from cardiovascular disease (Jackson et al, 2012; Chaturvedi et al, 1997).

2.1.5 Treatment of diabetes

The United Nations General Assembly has highlighted the importance of preventing and controlling non-communicable diseases including diabetes, calling for a strengthening of population level interventions as well as improving primary care services and disease monitoring (WHO, 2013)
Once a person has been diagnosed with diabetes, emphasis is on controlling the condition. Diabetes is a chronic condition, meaning it cannot be cured, so care is focussed on trying to prevent the person with diabetes from developing complications by controlling blood glucose. Control in diabetes generally refers to two measures of how much sugar there is in the blood: HbA1c and blood glucose level. The first is the HbA1c, which is a measure of blood glucose over a period of two to three months, it measures glycated blood (http://www.diabetes.co.uk/what-is-hba1c.html). It is advised that HbA1c is maintained below 6.5% (48 mmol/mol) for most people with diabetes and below 7.5% (58 mmol/mol) for those who are at greater risk of hypoglycaemia (Diabetes UK http://www.diabetes.org.uk/Guide-to-diabetes/Monitoring/Testing/; Rodbard et al, 2009). Although doctors and individuals with diabetes can agree on other achievable target levels in the latest National Institute for Clinical Excellence (NICE) guidelines for managing diabetes (NICE, 2009). The second measure, blood glucose is a measure of the concentration of glucose in the blood at the time of the test those with type II diabetes should aim to have blood glucose of 4-7 mmol/L before meals and under 8.5 mmol/L after meals (http://www.diabetes.co.uk/diabetes_care/blood-sugar-level-ranges.html).

There are several means to maintain blood glucose control, incorporating both medicines and lifestyle changes. The current NICE guidelines for treating diabetes include providing the person with diabetes with information to manage the condition, dietary advice, medication and monitoring of possible complications (NICE, 2009). Along with dietary change, people with diabetes can help to control their blood glucose by exercising (Knowler et al, 2002; Tulomilehto, 2001). This process of lifestyle change, following a medication regimen, attending healthcare appointments and self-monitoring often described as self-management.

In 2001 the Department of Health introduced the National Service Framework for Diabetes. This sets out minimum standards for care, including nine care processes which attempt to ensure the control and monitoring of blood glucose, cholesterol and blood pressure to minimise the risk of complications developing, and screening for preventable complications. The introduction of the framework does appear to have improved care for people with diabetes (Kontopantelis et al, 2013;
Khunti et al, 2007). Despite this, the DoH estimate that approximately 24,000 people a year die prematurely of complications related to type II diabetes.

2.1.6 Why is it important to study diabetes?

The prevalence of diabetes is growing due to the combination of an aging population, rising obesity and changing ethnic makeup of the population (Hex et al, 2012). Without improvement in treatment, this will lead to increased costs to the NHS, to society as a whole, and to personal cost and suffering of those with diabetes and those around them.

Type II diabetes is condition in which people are often unaware of their condition until a diagnosis is made through screening. This is unlike other chronic conditions such as heart disease, which can be signalled by an event (heart attack), or arthritis, where there is pain to bring the condition to the attention of the person with arthritis. Often a person does not know they are unwell due to the subtle nature of the symptoms of diabetes (outlined in 2.1.1). Despite this, people are expected to make considerable, sometimes complex changes to their everyday life following diagnosis. Not undertaking these changes often does not result in an obvious pain or discomfort feedback cycle, as it would in conditions with clearer physical symptoms such as irritable bowel syndrome. So people with diabetes are having to change their lives in sometimes quite drastic ways when they do not necessarily feel unwell, or they do not feel worse when not making these changes. This makes diabetes an atypical condition in terms of management and the Department of Health (2005) estimations cited above show that management support is not yet adequate to help people through this, resulting in the early death of a significant number of people with diabetes. Diabetes management is a pressing issue at personal, national and global levels. Ultimately, this study aims to increase understanding of what acts as a barrier to self-management and in doing so provide information to better support people with type II diabetes to manage their condition.
2.2 Study background: Collaborations for Leadership in Applied Health Research and Care

This study is nested in a large National Institute for Health Research funded Collaborations for Leadership in Applied Health Research and Care (hereafter referred to as the CLAHRC study) research project. The CLAHRC study aims to promote self-management support in primary care through researching patient need and designing self-care support interventions based on those findings. The CLAHRC study is not directed at a single long term condition as this study is, but a range of cardiovascular long term conditions.

The CLARHC study is divided into three phases: evidence synthesis, a mixed methods study of patient experience, and development and evaluation of a self-care support intervention or interventions. The study in this thesis is part of the second phase of the CLAHRC project, adding a specific focus on the experiences of those with diabetes through in depth semi structured interviews which were designed to supplement the interviews conducted during phase two.

2.2.1 Aims, objectives and structure of the Collaboration for Leadership in Health Research and Care study

The aims, objectives and methods of the CLAHRC study are considered in detail in the methods chapter (5.2.1) as well as how this study fits into the CLAHRC study, but for clarity a brief outline will be presented in this chapter.

The overarching aims of the CLAHRC study are to better understand the factors which influence the self-care of people with heart disease, diabetes and kidney disease and to use this information to feed into development of new self-care support interventions. The objectives of the CLAHRC study as outlined in the research proposal are outlined in box 2.1.
Box 2.1 Objectives of the CLAHRC study

- Explore the needs, experiences and practices of people who are socially disadvantaged and living with a long term condition
- Assess the support systems, access to social, personal and material resources, and how this influences self-management
- Modify existing self-management support and training materials through engagement with people with long term conditions.
- Develop new strategies to support self-care which are sensitive to the differing contexts of people living with long term conditions.
- Evaluate self-care support strategies developed as part of the study
- Cost-effectiveness evaluation

To achieve these aims and objectives the CLAHRC study was conducted over three phases as outlined above: data synthesis, data collection, development and evaluation of an intervention or interventions. See chapter five, section 5.2.1 for details on the methods employed in the CLAHRC study.

The primary aim of the study described in this thesis, to identify barriers to self-management experienced by people with type II diabetes, fits into and complements the empirical study conducted in the second stage of the CLAHRC study.

2.2.2 Theoretical background to the CLAHRC study

The CLAHRC study addresses the aim to improve self-care support for socially disadvantaged people by taking a socially orientated view of self-care support in contrast to the support currently in place, which “may be excessively focussed on individual’s capacity and responsibility to initiate and sustain strategies for self-management support” (Rogers et al, 2011). This is without regard to the circumstances of the person with the long term condition or the contexts in which the person will enact the practices associated with self-management. The CLAHRC study seeks to illuminate how contexts, resources, priorities and networks affect self-management practices in order to produce more flexible self-
management practices. To do this, the study is predicated on four main concepts: social networks, illness work (Corbin and Strauss, 1985; 1988), the normalisation process theory (May and Finch, 2009) and the Whole Systems Informing Self-Management Engagement (WISE) approach (Kennedy et al, 2007).

2.2.3 Social networks

Most self-management work takes place outside the health care system and open system of the person with the condition. These open systems are complicated networks of networks and systems of support comprised of friends, families, colleagues, community groups, health care professionals and non-health care professionals. Mapping these networks using the concentric circles method which presents the participant with three concentric circles getting smaller into the centre, they imagine themselves in the middle and map their social network onto the circles according to closeness and importance (Pescosolido, 1992) This method was used to describe how the responsibilities of self-management are distributed throughout the network. In acknowledging these contexts, the emphasis of self-care support may have to change to focus on the well-being of the person rather than simply on health related behaviour change (Rogers et al, 2011)

2.2.4 Illness management and types of work

The CLAHRC team expanded on the work of Corbin and Strauss (1985; 1988) which distinguish illness work from everyday work and biographical. Illness work is the work directly related to managing a long term illness including symptom management and crisis prevention. This is separated from the everyday work of housework, childcare, etc., and biographical work such as planning for the future. The CLAHRC research project sub-divides illness work into five categories:

1. Contingency/improvisation: work that gets things “back on track”
2. Translation and mediation: turning abstract knowledge into practical knowledge and practice
3. Co-ordination: negotiating how work will be done and by whom along with the practicalities of getting the work done,
4. Advocacy: negotiating the contributions and work of others on one’s behalf,
5. Emotional work: work done to calm oneself. (Rogers et al, 2011)

2.2.5 Normalisation

In order to manage long term conditions people often have to adopt new practices and change old ones. The CLAHRC project draws on the normalisation process theory (NPT) to describe the process by which illness management practices are embedded into everyday routines (May and Finch, 2009). The theory, which is described in detail in Chapter four, is a theory of implementation originally developed to describe the process of implementing complex interventions in healthcare settings but has since been applied in a variety of settings. The CLAHRC project, and this study in particular, draws on the NPT to understand how people embed illness work into their everyday lives (Rogers et al, 2011). Using the NPT allows for the examination of individual and social processes which lead to enacting practices and eventually normalisation.

2.2.6 Whole Systems Informing Self-Management Engagement

The work of the CLAHRC team draws from and builds on the work of WISE to look at what affects how people enact and embed illness management practices at different levels. The WISE approach aims to enable patients by providing opportunities for people with long term conditions to access and use more information through support and guidance from healthcare professionals who are working within a system better equipped to support the individual (Kennedy et al, 2010). In the WISE approach, the individuals are provided with information, healthcare professionals are trained in patient centred care, and changing the healthcare system to increase patient access to outpatient clinics and support (Kennedy et al, 2007). This multilevel, whole systems approach aims to better support people with long-term conditions with their self-management. So far the work of developing the WISE approach has been on healthcare systems, the work of CLAHRC was to extend the approach to broader social contexts. The CLAHRC study aimed to fill information gaps about the work conducted at different levels in order to inform new multilevel interventions.
2.3 Summary

This chapter introduces and the clinical and theoretical background in which this study was set.

Diabetes is a prevalent and costly condition, it is a condition that can be managed through medication and lifestyle change, but still people with diabetes are developing complications from the condition. This is not the first study which attempts to identify factors that prevent people from practicing self-management, the following chapter is a scoping review of previous research attempting to identify factors affecting diabetes self-management.
3 Literature Review: barriers to self-management in type II diabetes

3.1 Introduction

This review aims to identify barriers to self-management in type II diabetes by reviewing existing reviews in the field. There is a considerable body of work examining barriers to self-management in type II diabetes; a simple search on PubMed or similar databases leads to thousands of articles. To make this volume of literature more manageable this chapter will present a review of the reviews available which identify barriers to self-management in type II diabetes. The method for this is adapted from Smith and colleagues’ (2011) paper regarding conducting systematic reviews of systematic reviews. This review is a general review, rather than a systematic review.

It has been established in chapter 3 that diabetes is both a worldwide (Whiting et al, 2011) and national healthcare concern (Holman et al, 2011). It is possible to reduce the risk of complications by maintaining a HbA1c level below 6.5% (48 mmol/mol) for most people with diabetes and below 7.5% (58 mmol/mol) for those who are at greater risk of hypoglycaemia (Diabetes UK http://www.diabetes.org.uk/Guide-to-diabetes/Monitoring/Testing/; Rodbard et al, 2009). Certain self-management practices can help people with diabetes to maintain this desirable HbA1c level (Knowler et al, 2002; Tulomilehto, 2001). These include: adhering to a medication regime, making dietary changes, undertaking physical activity and monitoring feet and blood sugar. However, not all people with diabetes are undertaking these practices. The aim of this review is to establish what is preventing people from undertaking self-management practices in the face of potential complications.

3.2 Methods

To find relevant reviews the following databases were searched: Medline, CINAHL and PubMed. Combinations of the following keywords were used: diabetes, barriers, facilitators, factors affecting, self-management, self-care, illness-management, systematic review (see box 3.1).
This yielded 37 results. For each of these results titles and abstracts were searched, 13 were selected. Inclusion criteria were that the papers were reviews of literature relating to barriers to self-management in type II diabetes. Papers were excluded when they were single studies rather than reviews, reviews of interventions to improve self-management, reviews of factors affecting only type I diabetes. Three of the papers originally included were removed (Polzer and Miles, 2005; Thorpe et al, 2013; Whittemore, 2004) because on closer inspection the papers did not review literature adhering to the inclusion criteria.

Studies about interventions have become included in this review through being included in the reviews of barriers that are being reviewed here, but they are not the focus of this review and therefore reviews exclusively of interventions were not included.

Where reporting was ambiguous the original studies were referred to for clarification. Original studies were also referred to where confirmation was needed that the results were relevant to type II diabetes, many reviews which included papers on both type I and type II diabetes did not differentiate between the conditions in reporting the results.

There were no limits on the countries which the reviews, and the studies contained within them, came from. Despite the fact that the study in this thesis is a British study where self-management takes place in the context of socialised healthcare, this review takes an international perspective.

### Box 3.1: Search terms

\[
((\text{barriers}[\text{All Fields}] \text{ AND } (\"\text{self-care}\"[\text{Mesh Terms}] \text{ OR } \"\text{self}\"[\text{All Fields}] \text{ AND } \"\text{care}\"[\text{All Fields}] \text{ OR } \"\text{self-care}\"[\text{All Fields}] \text{ OR } \"\text{self}\"[\text{All Fields}] \text{ AND } \"\text{management}\"[\text{All Fields}] \text{ OR } \"\text{self-management}\"[\text{All Fields}]) \text{ AND } \"\text{diabetes mellitus}\"[\text{MeSH Terms}] \text{ OR } \"\text{diabetes}\"[\text{All Fields}] \text{ AND } \"\text{mellitus}\"[\text{All Fields}] \text{ OR } \"\text{diabetes mellitus}\"[\text{All Fields}] \text{ OR } \"\text{diabetes}\"[\text{All Fields}] \text{ AND } (\text{\"review\"}[\text{All Fields}] \text{ OR } \text{\"review literature as topic\"}[\text{MeSH Terms}] \text{ OR } \text{\"review\"}[\text{All Fields}])
\]
<table>
<thead>
<tr>
<th>Title of review</th>
<th>Authors</th>
<th>Year</th>
<th>Conditions included in review</th>
<th>Type of review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barriers to self-management of diabetes</td>
<td>Ahola and Groop,</td>
<td>2012</td>
<td>Type I diabetes and type II diabetes</td>
<td>General</td>
</tr>
<tr>
<td>Real-world factors affecting adherence to insulin therapy in patients with Type 1 or Type 2 diabetes mellitus: a systematic review</td>
<td>Davies et al</td>
<td>2013</td>
<td>Type I diabetes and type II diabetes</td>
<td>Systematic</td>
</tr>
<tr>
<td>How Diet Modification Challenges Are Magnified in Vulnerable or Marginalized People With Diabetes and Heart Disease</td>
<td>Vanstone et al</td>
<td>2013</td>
<td>Cardiovascular disease</td>
<td>Systematic</td>
</tr>
<tr>
<td>Barriers to diabetes management: patient and provider factors</td>
<td>Nam et al</td>
<td>2011</td>
<td>Type II diabetes</td>
<td>Systematic</td>
</tr>
<tr>
<td>Glucose control in diabetes: the impact of racial differences on monitoring and outcomes.</td>
<td>Campbell et al</td>
<td>2012</td>
<td>Type II diabetes</td>
<td>General</td>
</tr>
<tr>
<td>Factors influencing the ability to self-manage diabetes for adults living with type 1 or 2 diabetes</td>
<td>Wilkinson, Whitehead and Ritchie</td>
<td>2012</td>
<td>Type I diabetes and type II diabetes</td>
<td>Systematic</td>
</tr>
<tr>
<td>Barriers to the self-care of type 2 diabetes from both patients’ and providers’ perspectives: literature review</td>
<td>Pun, Coates and Benzie</td>
<td>2009</td>
<td>Type II diabetes</td>
<td>Systematic</td>
</tr>
<tr>
<td>Psychosocial Barriers to Diabetes Self-Management and Quality of Life</td>
<td>Glasgow, Toobert and Gillette</td>
<td>2001</td>
<td>Type I diabetes and type II diabetes</td>
<td>Meta-analysis</td>
</tr>
<tr>
<td>A qualitative synthesis of factors influencing maintenance of lifestyle behaviour change in individuals with high cardiovascular risk</td>
<td>Murray et al</td>
<td>2013</td>
<td>Cardiovascular disease</td>
<td>Systematic</td>
</tr>
</tbody>
</table>
3.3 Results

3.3.1 Individual Characteristics

3.3.1.1 Demographic

Adherence to insulin therapy was lower in older people, women, unmarried people, and those with lower HbA1c (Egede et al, 2011 in Davies et al, 2013). Due to the use of a survey study design, it is not clear why these people experienced more difficulty adhering to the insulin therapy.

In the case of there is a difference in how the sexes perceive dietary changes, women tend to view dietary change as a personal matter, while men view it as a family issue (Peel et al, 2005 in Vanstone et al, 2013). Women perceive less support from husbands than men received from their wives (Beverley et al, 2006 in Vanstone et al, 2013). It is possible that this extends to other self-management practices.

3.3.1.2 Self-discipline

Self-discipline was both a barrier and facilitator for people to adhere to dietary changes. The review found that descriptions of control were common in papers about people with diabetes, people feel that control over diet gives them the power to manage their blood sugar (Broom and Whittaker, 2004; Gutschall et al, 2011; Early et al, 2009; Gazmararian et al, 2009; Onwudiwe et al, 2011; White et al, 2011; McCloskey et al, 2010; Balfe et al, 2007 in Vanstone et al, 2013). The emphasis on self-discipline might explain frustrations experienced by people who adhere to dietary recommendations but do not see improvements in their blood sugar (Nagelkerk et al, 2006 in Vanstone et al, 2013).

3.3.1.3 Coping

Coping strategies were linked with self-management. Denial as a coping mechanism is linked to lower adherence to the lifestyle changes recommended for diabetes management (Gazmararian et al, 2009 in Ahola and Groop, 2012). Wish fulfilment as a coping strategy is less effective than employing a problem solving coping strategy (Kvam and Lyons, 1991). Better problem solving was also associated with healthier eating (King et al, 2010), better self-management.
(Primozic et al, 2012 in Ahola and Groop, 2012) and greater frequency of blood sugar monitoring (Wang et al, 2012 in Ahola and Groop, 2012). People who are successfully enacting self-management practices tended to employ strategies such as meal planning which demonstrates a problem solving style of coping (Murray et al, 2013)

3.3.1.4 Theory of Planned Behaviour, attitudes, beliefs, control and self-efficacy

Some studies turned to psychological theory to explain why some people enact self-management practices and some do not. The Theory of Planned Behaviour (Ajzen, 1991) states that behavioural intention is predicted by attitudes towards the behaviour, perceived behavioural control and social norms. This behavioural intention then goes on to influence actual behaviour. In the study of Gatt and Summat, (2008 in Ahola and Groop, 2012), the Theory of Planned Behaviour predicted 49% of the variance of intent to undertake diabetes self-management practices was explained by attitudes, subjective norms and perceived behavioural control. Perceived behavioural control accounted for most of the changes in behaviour.

In accordance with the Theory of Planned Behaviour there is an association between positive attitudes towards diabetes self-management practices and undertaking those practices. Beliefs about the benefits of medication were associated with adherence to the regime (Anderson, Donnelly and Dedrick, 1990; De Weerdt et al, 1990; Dunn, 1990 in Nam et al, 2011).

Attitudes affected whether people would undertake physical activity, with those who are active having positive attitudes towards exercise. They may believe it will make them feel healthy. On the other hand inactive people reported negative attitudes that they will feel sore after exercising (White et al, 2007 in Ahola and Groop, 2012). It is difficult to know whether the positive attitude to exercise comes from being an active person in the first place so therefore they did not experience the negative effects that people might experience when first implementing exercise into daily life. This study also found that people who did not exercise reported laziness as a barrier to taking up exercise, suggesting lower perceived behavioural control. Similarly when asked about diet those who
adhered to a diet low in saturated fatty acid perceived that the diet made them feel healthy. Social norms were also important to participants in the study with those that did not adhere to the diet reporting that they felt people in their social network would not approve of them having such a diet.

Health beliefs has been found to be one of the strongest predictors of self-management practices (Wilson et al, 1986 in Pun, Coates and Benzi, 2009). But shaping health beliefs is not simple, people with diabetes continue to question the benefits of a healthy lifestyle (Murray et al, 2013). Murray and colleagues speculate that this could be because where people enact practices, but do not see them reflected in HbA1c readings they become dubious about the benefits.

Perceived control over life events was associated with undertaking self-management practices and better glycaemic control (Sloan, Padron and Platt, 2009 in Ahola and Groop, 2012).

Self-efficacy describes the belief that a person has in their ability to succeed in specific situations (Bandura, 1994). Similar to perceived behavioural control, higher self-efficacy was associated with adherence to self-management practices and better glycaemic control (Chih et al, 2010 in Ahola and Groop, 2012). In fact, in their meta-analysis of 21 cross-sectional studies examining psychosocial barriers to self-management, Glasgow, Toobert and Gillette (2001) found that self-efficacy was the most strongly and consistently linked to undertaking self-management practices. The second most common was social support, which is linked to self-efficacy (Heisler and Piette, 2005 in Ahola and Groop, 2012). Of the practices associated with diabetes self-management people are most confident in their ability to adhere to their medication regime (Sharoni and Wu 2012 in Ahola and Groop, 2012; Ary et al, 1986in in Pun, Coates and Benzie, 2009). People are largely unsure of their ability to change their diet or start exercising, this is reflected in rates in which people undertake these tasks: 5.6 times a week for medication, compared to 3.5 for following dietary recommendations (Tang et al, 2008 in Ahola and Groop, 2012)

There are varying results relating to a third measure of control, locus of control, which assesses the level to which people believe they control their own behaviour or whether the control is external. It is unclear if diabetes management is affected
by locus of control with different studies reporting different results (Peyrot and McMurry, 1985; Sloan, Padron and Platt, 2009 in Ahola and Groop, 2012). Peyrot and Rubin (1994 in Ahola and Groop, 2012) separated internal diabetes locus of control into “autonomy” and “self-blame”. Autonomy was associated with higher levels of self-efficacy and emotional wellbeing, while self-blame was associated with binge eating more often. This shows that while internal locus of control can be empowering and can enable people to enact recommended self-management practices, it can also lead to a person blaming themselves for mistakes and have negative consequences for self-management (Ahola and Groop, 2012). Less sense of personal control was associated with lower adherence to insulin therapy (Broadbent et al, 2011 in Davies et al, 2013). This study also found that people who did not adhere to medication regimes had a higher perception of the consequences of diabetes which is not in line with expectations from the Theory of Planned Behaviour.

3.3.1.5 Stress

Emotional stress inhibits adherence to diabetes related dietary changes (Gutschall et al, 2011; Clark et al, 2011; Dussart et al, 2009; Jacobsson et al, 2004 in Vanstone et al, 2013). As a diagnosis of diabetes can potentially cause stress and fear for people with the condition (Vanstone et al, 2013) this can cause a pervasive and ongoing barrier.

3.3.1.6 General

Wilkinson and colleagues (2014) report a large amount of data pertained to psychological factors including the following themes “acceptance”, “adherence”, “denial”, “integration”, “quality of life”, “partial integration” and “lack of integration”, “acceptance”, “reluctance to change” and “frustration at inability to achieve self-management ideals”. However, this isn’t expanded on in the review so lacks detail.

3.3.2 Knowledge

3.3.2.1 Benefits of knowledge

The benefits of knowledge are inconsistent according to the review by Nam and colleagues (2011). People with diabetes will undertake risky behaviours despite
being aware of possible repercussions (Avis et al., 1990 in Nam et al., 2011). Better knowledge leads to better self-management practices, but this was not reflected in blood sugar levels (Persell et al., 2004 in Nam et al., 2011)

Other reviews report that there is a positive association between diabetes knowledge and self-management practices and that lack of diabetes knowledge is a barrier (Ahola and Groop, 2012; Vanstone et al., 2013). Lack of knowledge about diabetes (Nagelkerk, et al. 2006 in Ahola and Groop, 2012 and Pun, Coates and Benzie, 2009) and poor understanding of self-management practices (Nair et al., 2007 in Ahola and Groop, 2012) is associated with lower adherence to self-management regimes. Knowledge about diabetes is related to a range of self-management practices including dietary changes, exercise, adhering to medication regimes and attending to monitoring (Heisler et al., 2002 in Ahola and Groop, 2012). This is particularly a problem for older people with diabetes who have poorer comprehension of diabetes related information (Peg et al., 1991; Mutch and Dingwall-Fordyce 1991 in Ahola and Groop, 2012). This is also seen in the relatives of older people with diabetes, affecting social support. The presence of knowledge about diabetes is a facilitator to dietary change, empowering people with diabetes, improving self-efficacy and providing motivation (Broom et al., 2004; McCloskey et al., 2010; Beverly et al., 2008; Chlebowy et al., 2010 in Vanstone et al., 2013).

People with diabetes feel that they need more information and education about the basics of their condition, such as why they have to monitor their blood sugar and how to reduce risks (Gazmararian et al., 2009 in Ahola and Groop, 2012). This suggests that the information is not presented to people with diabetes in a form that allowed for satisfactory retention of knowledge and understanding.

### 3.3.2.2 Health literacy

With knowledge a largely positive influence on self-management, barriers to attaining and retaining diabetes knowledge should be considered. Poor vision and literacy problems are a barrier to acquiring knowledge (Rhee et al., 2005 in Pun, Coates and Benzie, 2009)

A review published on health literacy and health outcomes in diabetes found that the quality of evidence on the effects of health literacy as a facilitator to self-
management was largely insufficient to determine an effect. Four studies included in the review examined the link between health literacy and lifestyle change related self-management practices across diet, exercise, blood sugar testing, foot care, smoking cessation, and adherence to medication (Bains and Egede, 2011; Mancuso, 2010; Kim et al, 2004; McCleary-Jones, 2011 in Al Sayah et al, 2013). These studies were adjusted for possible confounding demographic factors and the review reports that they found no association. Although on further examination of the relevant papers it was discovered that a positive, but not significant association was found, this lead to the authors’ conclusion that there was moderate evidence for a positive association between health literacy and self-management practices.

The review of the role of health literacy in diabetes management (Al Sayah et al, 2013) reported one study which found a link between health literacy and self-management support (Osborn et al in Al Sayah et al, 2013). Therefore health literacy indirectly affects self-management practices through social support which is an important aid to self-management.

A lower level of health literacy is associated with the inability to remember instructions regarding medication and poor glycaemic control (McCarthy et al, 2012, Schillinger et al, 2002 in Ahola and Groop, 2012)

### 3.3.2.3 Information delivery and learning style

Wilkinson and colleagues (2014) report that education should be tailored to the understanding and needs of the individual and their partner. These needs included specific dietary advice tailored to culture and preferences. The message had to be consistent and there was some evidence that repeating and building on key facts supported knowledge acquisition.

Learning style should also be taken into consideration. When learning about diabetes, most learning was done either by “experimental learning” or “vicarious learning” rather than the formal, didactic information imparted by healthcare professionals. People with diabetes learn through observing the self-management efforts of other people with diabetes. Through this they learned about the demands of self-management, and how likely they were to achieve success, and

3.3.3 Interactions with healthcare professionals

3.3.3.1 Relationships and interactions with healthcare professionals

Perceptions of how healthcare professionals delivered information was identified as a potential barrier. People with diabetes who perceived that their healthcare professional was impolite felt that their experiences, feelings, traditions, and values were not respected by the healthcare professional potentially impeding implementation of self-management practices. Similarly, perceived discrimination was also identified as a barrier. (Wilkinson et al, 2014)

Good relationships between healthcare professionals and people with diabetes are associated with both better self-management, and better diabetes outcome. In the case of a poor relationship, with the absence of collaborative care a negative effect on adherence can be observed (Nam et al, 2011). Individuals with diabetes preferred healthcare professionals who provided tailored care and self-management support. Extra care from providers was very much appreciated by people, particularly when it was seen as “beyond the call of duty” (Wilkinson et al, 2014).

For people with diabetes a good quality relationship with healthcare professionals is important for improving self-management. People with diabetes express that a desirable relationship with their healthcare professional include the ability to listen attentively, providing sufficient amounts of time for the consultation, providing information about the condition and explaining why treatment decisions are made (Nair et al, 2007 in Ahola and Groop, 2012). However, this is not the experience of most people with diabetes who find that their doctor makes decisions and they are expected to comply (Mosnier-Pudar et al, 2009 in Ahola and Groop, 2012). Where there was partnership between the healthcare professional and person with diabetes, the person with diabetes was more likely to report making diabetes related lifestyle changes (Mosnier-Pudar et al, 2009 in Ahola and Groop, 2012).
People with diabetes want consistent access to regular healthcare professionals. They find seeing healthcare professionals who do not know their history or for inadequate amounts of time frustrating. People wanted to be involved in shared decision making and to build on self-management skills over time (Wilkinson et al, 2014).

There is a tension between people who want to be in charge of their own decisions but also wanting their healthcare provider to be in charge of their health. (Wilkinson et al, 2014)

Higher levels of health literacy was associated with better patient provider interactions through perceptions of information and participation in decision making (Ishikawa et al, 2009 in Al Sayah et al, 2013) and having less paternalistic interactions with healthcare professionals (Arthur et al, 2009 in Al Sayah et al, 2013)

Support from a diabetes nurse facilitates adherence in people at the beginning of an insulin based medical regime (Lerman et al, 2009 in Davies et al, 2013)

**3.3.3.2 Shared understanding diabetes and self-management practices**

Healthcare professionals and people with diabetes do not share the same thresholds for concern about developing complications from diabetes. People with diabetes estimate the risk of having higher weight, waist circumference and HbA1c as lower than healthcare professionals (Clark and Hampson, 2001 in Ahola and Groop, 2012) which signals of a lack of communication. In the work of Chin and colleagues (2001 in Pun Coates and Benzie, 2009) doctors report that they put greater emphasis in self-management practices than how they perceive their patients view the same practices. Where individuals struggled to communicate their needs and feelings to healthcare professionals, those professionals could not attend to the unexpressed needs of the person with diabetes therefore acting as a barrier to self-management. (Wilkinson et al, 2014)

There are reported knowledge deficits between medical understanding and the understanding of diabetes among people with the condition in several key areas. This is not exclusive to people from the “vulnerable” populations who are the focus of the Vanstone review, but the following papers are about people from
these populations. Knowledge deficits include practical knowledge about which foods are recommended to help control diabetes (Kieffer et al, 2003 in Vanstone et al, 2013), understanding counting calories and carbohydrates (Early, 2009 in Vanstone et al, 2013), and understanding what was classed as vegetable and what is carbohydrate (Wood et al, 2005 in Vanstone, 2013). As well as the practical knowledge needed to implement healthy dietary changes, there was also a deficit in knowledge about diabetes and complications resulting from the condition (Rahim-Williams et al, 2011; Coronado et al, 2004 in Vanstone et al, 2013) how diet affects blood sugar, for example (Skelly et al, 2006; Fritschi et al, 2010; Holmstrom et al, 2005 in Vanstone et al, 2013). Vanstone et al raise the difficulties evaluating whether this knowledge deficit arises from poor recall of information, or whether there has not been the opportunity to acquire diabetes relevant information (Doyle et al, 2012). This paper concerns those with heart disease, but the distinction remains relevant in the context of people with type II diabetes.

### 3.3.3.1 Attitude of healthcare professionals to diabetes and diabetes care

The attitudes of doctors towards diabetes and diabetes management affects the self-management of the individual, with the beliefs and attitudes of the clinician influencing adherence to medication regimes in the person with diabetes (Puder and Keller, 2003, in Nam et al, 2011). Behaviour at the time of the diagnosis was particularly important, where clinicians downplayed the seriousness of the condition to comfort patients (often in distress). As a result, diabetes was considered by patients to be a less serious condition than it actually is (Dietrich, 1996, in Nam et al, 2011). Attitude to insulin therapy was influenced by the attitude of the prescribing doctor (Hunt, Valenzuela and Pugh, 1997, in Nam et al, 2011) with a negative attitude on the part of the doctor affecting the attitude of the person with diabetes.

Some healthcare professionals find managing diabetes labour intensive because of the amount of work associated with monitoring the condition or frustrating because of the unsure prognosis of the condition (Larme and Pugh, 1998 in Ahola and Groop, 2012)
3.3.4 Social Support and Barriers

3.3.4.1 Benefits of social support

Social support is largely a positive influence on self-management (Wilson et al, 1985; Wang and Fenske, 1996 in Pun, Coates and Benzie 2009; Murray et al, 2013). In a study of social support 43% of participants reported that their doctor was their primary source of support, followed by 20% of participants who said their spouse, and 19% who said another family member (Tang et al, 2008 in Ahola and Groop, 2012). In this study 8% of participants reported having no social support at all. This social support was positively associated with undertaking self-management practices including diet, exercise, taking medication and monitoring.

Social support is also associated with perceived self-efficacy to perform self-management practices (Heisler and Piette, 2005 in Ahola and Groop, 2012) which is in turn associated with better self-management. Support also affects perceived barriers to self-management and is associated with mortality and morbidity (Bayliss et al, 2003; Cohen, 2004 in Nam et al, 2011). However, this effect is complicated. For instance, women lost more weight when their partners were involved in weight loss education groups, but, for men, having their partner present negatively impacted weight loss (Wing et al, 1991, in Nam et al, 2011).

Social support was particularly important to getting exercise. Having a person to be active with in a social way facilitated physical activity (Murray et al, 2013)

Another review is entirely positive about the role of support from partners. This support was reported as very important, partners reminded people with diabetes to undertake practices, provided feedback on behaviour and symptoms, and noticed problems. Where this is absent it is a significant barrier to self-management, this is particularly a problem for women as husbands were less supportive (Wilkinson et al, 2014). Having a spouse who did not understand the importance of diabetes management was associated with lower adherence to insulin (Ary et al, 1986 in Davies et al, 2013)
3.3.4.2 Types of support

Emotional support (understanding and respect for needs) is potentially a greater facilitator to implementing dietary changes than practical support (Carter-Edwards et al, 2004 in Vanstone et al, 2013). Positive support (encouraging, reminders, empowering) is a better facilitator to dietary change than negative support (nagging, restricting) (Beverly et al, 2008; Carter-Edwards et al, 2004; Paisley et al, 2008 in Vanstone et al, 2013). It is unclear if negative support is more or less of a barrier than an absence of any kind of support.

Emotional support from family members helped people with diabetes to view dietary change as possible (Early et al, 2005 in Vanstone et al, 2013) and practical support such as buying only healthy food enabled people with diabetes to manage their condition (Gutschall et al, 2006 in Vanstone et al, 2013). Friends and family members who also had the condition under control acted as a motivator to change dietary practices (Lohri-Posey et al, 2006; Parker et al, 2011 in Vanstone et al, 2013). Concern about the condition from family and friends also encouraged adherence to dietary recommendations (Wellard et al, 2008 in Vanstone et al, 2013). However, this concern can also act as a barrier by becoming stressful for the person with diabetes, especially if the concern is focussed on an issue the individual cannot or does not want to change (Lohri-Posey et al, 2009 in Vanstone et al, 2013). Another way in which it can act as a barrier is when the support from the social network replaces the role of the person with diabetes in managing their condition, leaving the social network to make decisions related to diet and monitor calorie intake (Beverly et al, 2008 in Vanstone et al, 2013).

For women whose partners were perceived as overprotective, benefits of an intensive patient education programme were less than for those where this was not the case (Hagedoorn et al, 2006 in Ahola and Groop, 2012).

who act as intermediaries for information and impact self-management that way. It is unclear from the review whether this was positive or negative or how it impacted on self-management practices.

3.3.4.1 The conflict between the needs of the social network and self-management

People with diabetes struggled with having to put managing their condition over the needs of their family (Carter-Edwards et al, 2004 in Vanstone et al, 2013). Prioritising the requirements of self-management over the family, for example preparing healthy foods that were not to preferences of the family or diverting financial resources into self-management, caused emotional stress (Denham et al, 2007; Nagelkerk et al, 2006 in Vanstone, 2013). Acting as a carer to others potentially acts as a barrier where the needs of others are put above the needs of the individual with diabetes (Wilkinson et al, 2014)

A variety of family and occupational responsibilities, such as busy work schedules and managing the needs and preferences of family members at meal times, are barriers to adhering to dietary recommendations. This includes regulating meal times as well as what is consumed (Mellin-Olsen et al, 2005; Kieffer et al, 2004; Mian et al, 2009; Carter-Edwards et al, 2004; Denham et al, 2007; Parker et al, 2011; Penn et al, 2008 in Vanstone et al, 2013). Some people with diabetes struggle to refuse prohibited foods when people in their social network are consuming those foods (Lohri-Posey et al, 2009 in Vanstone et al, 2013)

Qualitative studies found that the dietary changes recommended for diabetes control were incompatible with social dining for South Asian people and people from Black African and Caribbean populations (Ziemer et al, 2003; New et al, 2003 in Wilson et al, 2012; Wilkinson et al, 2014) which affected the ability of people from these ethnic minorities to enact dietary changes.

Families are not always reported to be supportive. Only 13% of participants in a French survey study reported that family had made any adjustments to their own lives to support diabetes management (Mosnier-Pudar et al, 2009 in Ahola and Groop, 2012)
3.3.5 Culture and Race

3.3.5.1 Burden of diabetes

There are discrepancies between barriers experienced by people from the dominant culture and race in the given country, and those experienced by ethnic minorities. A lot of literature has been dedicated to exploring these barriers. Black women in America reported more barriers to diabetes self-management than white women. These included greater financial barriers, more diabetes-related pain and more visual barriers to management (Schoenburg and Drungle, 2001 in Pun, Coates and Benzie, 2009). Black Americans were less likely than White Americans to monitor blood sugar and have less control over blood sugar (Campbell et al, 2012)

3.3.5.2 Access to care

A systematic review examining access to care for people with diabetes from ethnic minorities (Wilson et al, 2012) found a variety of ways in which people from ethnic minorities find it more difficult to access care. This review included both barriers to accessing care and randomised controlled trials for interventions to improve access to care, for the purposes of this study only the results relating to barriers are included. The studies contained in the review include survey studies, trials, and qualitative studies. Black African and Caribbean people and people of South Asian descent were the focus of the systematic review, which concluded that people from those populations experience more difficulty accessing care than white populations and that this impacts on self-management. There were a variety of reasons for this finding including communication with healthcare providers, language, cultural misunderstanding, inadequate information and poor awareness of services. This impacted on self-management through problems with how much knowledge and understanding people with diabetes had about their condition (Hawthorne, 2001; Hawthorne and Tomlinson, 1999, in Wilson et al, 2012). This was a particular problem for people from South Asian populations where language and literacy can be a barrier to care (Mainous et al, 2006; Hawthorne and Tomlinson, 1999, in Wilson et al, 2012). There was some evidence which suggested that people from ethnic minorities were less likely to adhere to medication regimens, worrying about possible side

In America having no English (in this case speaking Spanish exclusively) was significantly associated with being unable to understand prescriptions and is reflected in monitoring practices (Campbell et al, 2012). This potentially impacts on the ability of people who do not speak the native language of their country to manage their diabetes. (Lasater et al, 2001 in Nam et al, 2011; Wilkinson et al, 2014). In America language and literacy problems prevent adequate communication between the person with diabetes and healthcare professionals, acting as a barrier to self-management (Dagogo-Jack et al, 2006 in Nam et al, 2011). Another review emphasises the importance of language, suggesting that the extensive barriers to self-management for some people from South Asian populations, which are not experienced by people from white populations, are language based because while African and Caribbean have some cultural barriers that are not experienced by white people, English is a more common language in these groups (Stone et al, 2006 in Wilson et al, 2012) and the barriers are not as significant.

3.3.5.3 Cultural incompatibilities with self-management

The diet regimen recommended for people with diabetes in not compatible with the traditional South Asian diet (Fagerli et al, 2005 a, b in Wilson et al, 2012). Wilson et al suggest this may be a result of poorer access to healthy food in Indian and Pakistani people (Lawton et al, 2007 in Wilson et al, 2012) or possibly to lower resources in these populations (Bissell et al, 2004 in Wilson et al, 2012). Sometimes foods not recommended for a diet aimed at diabetes control have cultural significance such as rice (Chesla et al, 2009 Culhane-Pera, 2007; Lawton et al, 2008; Finucane, 2008 in Vanstone et al, 2013)

People sometimes ate prohibited foods because those foods were linked to identity and belonging (McCloskey et al, 2010; Chesla et al, 2009; Culhane-Pera et al, 2007; Lawton et al, 2008, in Vanstone et al, 2013). Where people did not like the recommended foods there was little motivation to change (Kieffer et al, 2004). In the UK people from other cultures sometimes perceive British foods to
be boring (Lawton et al, 2008 in Vanstone et al, 2013). In Chinese culture freedom to enjoy food is important to quality of life (Yao, Chung and Wang, 2002, in Nam et al, 2011)

For some cultures dietary changes are not compatible with cultural perceptions of health and illness where certain foods, such as rice, are considered important for health, this is not always in line with recommendations for managing diabetes (Chesla, Chun and Kwan, 2009; Chun et al, 2004 in Vanstone et al 2013)

Cultural norms may act as a potential barrier through how people view health and weight, Bangladeshi people have a higher acceptance for larger body types (Greenhalgh et al, 1998 in Wilson et al, 2012; Wilkinson et al, 2014) and reluctance to view themselves as overweight (Khanam and Costarelli, 2008 in Wilson et al, 2012).

Cultural sensitivity is important in presenting knowledge in a manner which will enable the person with diabetes. Vanstone et al (2013) use the example of Warlpiri Aboriginal people in Australia who value personal control. As such they do not perceive advice from healthcare professionals positively, as being told that something is prohibited reduces personal control (Dussart et al, 2009).

People living far away from their own culture may also experience extra stressors, potentially increasing the emotional barriers to self-management (Culhane-Pera et al, 2007; Mellin-Olsen et al, 2005; Wallin et al, 2007; Sulaiman et al, 2007; Vincent et al, 2006 in Vanstone et al, 2013)

### 3.3.5.4 Spiritual beliefs

Spiritual beliefs that the outcome of diabetes was in God’s hands negatively affected diabetes management (Wilkinson et al, 2014). This is disputed by the work of Polzer and Miles (2005) who cite the interaction between health and spirituality in African American culture in relation to other conditions as evidence that spiritual beliefs can improve disease management. The Polzer review was removed from this study due to the literature reviewed relating to diabetes self-management on tangentially but the findings are cited in the Ahola et al (2012) paper which is included in this review. The importance of understanding how culture affects diabetes management is exemplified by the work of Caban and
Walker (2006 in Nam et al, 2011) which showed that beliefs about the causes if diabetes, the role of God and use of folk healers differed between Hispanic cultures.

3.3.5.5 Social support

Although people from non-white backgrounds were largely disadvantaged in managing diabetes in countries where white is the dominant culture, this was not universal. People from African American backgrounds reported better social support from family and friends (Fitzgerald et al, 2000, in Nam et al, 2011) and this support was more positively viewed than by white American counterparts. However, this effect was not seen across all minorities; the cultural beliefs of Mexican Americans were a bigger barriers to implementing and embedding self-management practices than were financial barriers. This was true even in socially disadvantaged, urban populations, because adhering to self-management practices was considered selfish and culturally the family comes before the self (Lipton et al, 1998, in Nam et al, 2011).

3.3.6 Financial barriers

Financial limitations affect the ability of the person with diabetes to buy healthy food, exercise equipment, supplies for blood glucose monitoring, and attend healthcare appointments (Vijan et al, 2005 in Pun Coates and Benzie, 2009; Wilkinson et al, 2014). People miss appointments due to lack of funds for transportation (Jerant et al, 2005 in Nam et al, 2011). In an American study those with lower household income were more likely to skip insulin injections (Peyrot et al, 2010 in Davies et al, 2013)

Although less relevant in countries like the UK with socialised healthcare, lack of insurance cover is a significant barrier to management. In an American study, 60% of people diagnosed with diabetes who were not covered by health insurance did not follow up with treatment, this is compared to only 6% of those with health insurance (Kuo et al, 2003 in Nam et al, 2011). Another American study reported that inadequate health insurance was significantly associated with inconsistent use of medication which was related to all-cause mortality (p=0.003) and diabetes related mortality (p=0.002). People without insurance report cutting medication
in half to prolong the length of time between prescriptions (Burge et al., 2000 in Nam et al., 2011)

Social disadvantage can compound emotional barriers through the stress of financial insecurity and not being able to make the recommended changes (Nagelkerk et al., 2006; Chlebowy et al., 2010; Cavanaugh et al., 2008 in Vanstone et al., 2013).

3.3.7 Comorbidities

3.3.7.1 Physical comorbidities

Comorbidities had a negative impact on diabetes via “impact of symptoms” and “lack of energy”. Poor vision, cognitive impairment and hearing problems can make reading labels, checking feet, driving and exercise difficult. Other conditions took precedent over managing diabetes. (Wilkinson et al., 2014; Bayliss et al., 2003; Bayliss, Ellis and Steiner, 2007 in Nam et al., 2011)

3.3.7.2 Depression

Co-morbid depression in people with type II diabetes is associated with increased morbidity and mortality (Lustman et al., 2000; Cho et al., 2005 in Nam et al., 2011). Depression is a problem in diabetes. People with diabetes are twice as likely as people without chronic disease to suffer an episode of depression (Anderson et al., 2001; Peyrot and Rubin, 1997 in Nam et al., 2011). This is presents a barrier to management as depression may negatively influence the perception of self-management practices. There is also a bi-directional effect between depression and social support which can act as a barrier to self-management. Meaning that depression affected the ability of people with diabetes to make and maintain friendships, and lack of social support worsened depression (Friedman, Brown, Romero, 2005; Vanderhorst and McLaren, 2005 in Nam et al., 2011)

Depression also acts on self-management through loss of interest, reduced decision making and fatigue associated with depression (Egede and Ellis, 2008; Egede and Osborn, 2010 in Ahola and Groop, 2012). This is also seen as a result of mild depressive symptoms (Gonzalez et al., 2007 in Ahola and Groop, 2012). The relationship between depression and glycaemic control is unclear, one meta-
analysis of 2817 of people with type I and type II diabetes found that depression was associated with poor glycaemic control (Lustman et al, 2000 in Ahola and Groop, 2012), whereas another of 1540 people did not show an association (Engum et al, 2005 in Ahola and Groop, 2012). It is suggested that the association may be present in people with type I diabetes but not type II (Ciechanowski et al, 2003 in Ahola and Groop, 2012). Where depression is associated with poor self-management it may be that depressive symptoms reduce self-management, but also that increased blood sugar may affect depressive symptoms (Ahola and Groop, 2012)

3.3.8 Medication

3.3.7.1 Side effects

Sexual activity can be affected by medication for diabetes which can act as an inhibitor to adhering to medication regimes. (Wilkinson et al, 2014)

3.3.7.2 Regime

Simple medication regimes made adherence easier. Participants who only had to take medication once a day were more likely to adhere to their regime than those who had to take medication on multiple occasions (Dezii, 2002 in Nam et al, 2011). Similarly those who had to take more than one drug (Dailey et al, 2001 in Nam et al, 2011), or who were on insulin rather than oral medication were less likely to adhere (Rajagopalan et al, 2003 in Nam et al, 2011). Contextual barriers such as travelling, being away from home or being too busy acted as a barrier to insulin injections (Ary et al, 1986 Peyrot et al, 2012 in Davies et an, 2013) more complicated routines will be more susceptible to such barriers.

3.3.7.3 Insulin

For approximately 33% of people with diabetes who have not been treated with insulin, there is a resistance to begin treatment with insulin if it is prescribed (Polonsky et al, 2003; Larkin et al, 2008 in Nam et al, 2011). Participants in studies believed that a prescription of insulin was due to personal failure to manage their diabetes, that insulin would lead to a more restrictive life, and that insulin could worsen the condition (Davis and Renda, 2006 in Nam et al, 2011). Pain on injections, embarrassment about taking injections, and injections causing
interference in everyday activities all acted as a barrier to injecting insulin (Peyrot et al, 2010 in Davies et al, 2013) as did fear of the pain of injections (Davis and Renda, 2006 in Nam et al, 2011)

3.3.8 Other

3.3.8.1 Choosing and controlling diet

People admit to regularly eating foods which potentially increase blood glucose because they desired those foods (Gazmararian et al, 2009 in Vanstone et al, 2013).

Portion control was difficult for many people with diabetes (Vijan et al, 2005 in Pun Coates and Benzie, 2009), and was viewed in several studies as laborious involving weighing everything that was eaten (Skelly et al, 2006; Wallin, 2007; Mian and Brauer 2009 in Vanstone et al, 2013). People often felt hungry when trying to implement portion control (Lohri-Posey, 2006). This hunger was compounded by increasing exercise at the same time as introducing smaller portions (Balfe, 2007; Malpass, 2009). This is possibly more common in people from ethnic minorities because of communication problems which result in the person with diabetes developing a misunderstanding of what is meant by portion control (Lawton et al, 2008; Lohri-Posey, 2006 in Vanstone et al, 2013)

3.3.8.2 Fear of hypoglycaemia

Fear of hypoglycaemia occurs in people with type II diabetes (Barendse et al, 2012 in Ahola and Groop, 2012), which can lead to poor management where people maintain hyperglycaemia to avoid the possibility of hypoglycaemia (Goebel-Fabbri et al, 2008 in Ahola and Groop, 2012)

3.3.8.3 The effect of employment

General fatigue from work negatively affected self-management (Wilkinson et al, 2014). Busy work schedules can affect meal planning and times (Vanstone et al, 2013)

3.4 Discussion

The barriers to self-management are wide ranging, complicated and interact with one another. These were grouped into themes of: individual differences,
knowledge, interactions with healthcare professionals, social support, culture and race, financial, co-morbidities. Anything which did not fit was labelled as other. Individual differences, in particular self-efficacy/perceived behavioural control and health beliefs/attitudes and social support seem to be particularly important.

Culture and race are also important, as a result a lot of literature focussed on the barriers experienced by people from races and cultures which are not dominant in the countries in which they reside. There are discrepancies between the barriers experienced by ethnic minorities compared to those experienced by people from the dominant culture. Specifically, this refers to ethnic minorities living in predominantly white, Western cultures. The studies included in this review included papers from the UK, Australia and America and examine barriers to self-management for indigenous populations, people from South and East Asia, and people from African or Caribbean origins.

This is also true of other socially disadvantaged groups. Financial insecurity acted as a barrier to eating healthily worldwide and to taking medications in countries which had for profit health services. Lack of knowledge, poor understanding and low literacy prevented people learning how to manage their condition, develop an understanding how to do this.

Health literacy also affected relationships with healthcare professionals, which had a distinct impact on the ability of people to self-manage. Negative relationships with healthcare professionals, where people did not experience coherent care from attentive professionals who understood their individual case was a barrier to communication and self-management. This could lead to differences in perceptions between healthcare professionals and people with diabetes contributing to lack of knowledge, denial style of coping and a negative attitude.

Co-morbidities, both physical and psychological negatively impacted self-management. Physical symptoms prevented physical activity and acted as a barrier to knowledge acquisition through poor sight. Depression acted on physical activity through fatigue and had a bi-directional relationship with social support.
3.5 Limitations

The very large literature on diabetes made it impossible to search, read, and review all the publications on self-management. For this reason, this review concentrated on the many reviews which have already been carried out. Much of the review is therefore influenced by the decisions of previous reviewers. Better quality reviews have greater representation in this review, this may not reflect the actual studies included in the reviews or the broader literature regarding barriers to self-management in type II diabetes.

The Al Sayah et al (2013) review, in particular, was problematic. Non-significant results were labelled negative which lead to statements about associations being difficult to interpret for this review. In these cases the authors reported that the studies showed no association, rather than they did not show an association which was misleading. For this reason the relevant original papers were referred to for clarity. Searching original papers was not always possible where some reviews did not clearly reference which papers results came from, such as Wilkinson et al and Murray et al.

The inclusion of the Polzer and Milne (2005) paper in Ahola and Groop (2012) raises questions about inclusion in studies. The literature reviewed by Polzer and Milne was deemed irrelevant to this study because the authors made inferences about diabetes management based on other conditions, but did not review literature directly related to barriers to self-management of diabetes. However, Ahola and Groop did include the paper in their review, meaning it was included here briefly because it was deemed worthy by another reviewer. This raises questions about the inclusion and exclusion criteria of review papers included in this review and whether or not papers would have been deemed relevant to this review had they been assessed directly.

The reviews included often focussed on particular groups (e.g. Vanstone et al, 2013), this was often relevant to this study due to the emphasis on understanding barriers to people who are somehow social disadvantaged. It is possible that potential barriers to the wider population were missed because of this focus. However, there is a spread of reviews looking at different types of potential barrier.
Having a single reviewer assessing papers for inclusion makes the potential for missing relevant papers more likely, but repeated searches were made to try to avoid this happening. Another pitfall of having a single reviewer is that there were no challenges as to whether certain papers met the inclusion criteria, or of the interpretation and selection of material from the chosen sources. Each was carefully considered, but this was unavoidable.
4 The Normalisation Process Theory

4.1 Introduction

This chapter addresses the second aim of this thesis which is to evaluate how useful the normalisation process theory (NPT) can be when applied to individuals operating in “open systems”. The chapter three looked at the barriers people experience when trying to implement change into their everyday routines, organisations also have some trouble implementing change with as many as 30% of interventions failing to become part of routine in complex settings such as health care (Grol, 2003). Complicated systems such as the NHS, and other healthcare systems have many potential barriers to implementation these include structural (financial), organisational (lack of resources, skills or equipment), peer (where the new intervention does not fit with local priorities), and at the professional – patient level (communication) (Southon and McDonald, 1997; Ferlie and Shortell, 2001). This translational gap has become the focus of increasing amounts of research in the health services field (Eccles and Grimshaw, 2004). The normalisation process theory (NPT) is a theory that seeks to explain and explore implementation of complex interventions in health care settings (May, 2006; May and Finch, 2009; May, 2013), in particular phenomena that result from co-operation and collective activities performed by actors, but which are experienced by individuals. This chapter is split into two main sections: the first will introduce the NPT while the second will look at the applications of the theory to date and how successful these applications have been. The NPT, developed from May’s original normalisation process model (NPM May, 2007), is a relatively recent theory, having been published for the first time in 2009 (May and Finch, 2009). Since the original May and Finch (2009) paper some work has gone towards further developing and clarifying the theory (May, 2013) this chapter attempts to pull together these works to provide the reader with a coherent understanding of the NPT, most importantly the NPT as it was applied during in this thesis. Having described the theory in the first section, the chapter will attend to how the both the NPT and the NPM may be applied and how successful these applications have been to date. The final aim of the chapter is to introduce the use of the NPT to examine how individual people implement
healthcare related practices in their open systems in line with the application of the NPT in this thesis.

4.2 Description of the normalisation process theory

4.2.1 What is meant by normalisation?

Normalise is a word that is quite commonly used outside of the social science sphere, as such it is important to define exactly what is meant by normalization in the context of the NPT and this thesis, where normalisation refers to the routine embedding of an intervention into everyday practice (May et al, 2007). There are other possible outcomes of an attempt to implement an intervention, these are adoption, where an intervention is taken up but does not become routine, or rejection, where users do not take up an intervention or subvert it. De-normalisation can also occur, when an intervention which has been normalized is superseded, disrupted or deteriorated.

4.2.2 What does the normalisation process theory aim to achieve?

The NPT seeks to fulfil the criteria outlined by May that theory should enable three kinds of work (http://www.normalizationprocess.org/theory-behind-npt/what-is-a-theory.aspx). The first is accurate description; a theory should present a set of definitions that allows for the differentiation, identification and codification of a set of phenomena. The second states that a theory will offer systematic explanation of the mechanisms at work and should propose their relation to other phenomena. Finally the theory must allow for knowledge claims or prediction. May also states that a fourth but not mandatory component is that the theory should be testable either through logic or empirical research. Similarly Bem and Looren de Jong (1997) describe a theory as a “coherent and non-contradictory set of statements, concepts, or ideas that organises, predicts or explains phenomena, events or behaviour” This chapter will examine if and how these criteria are fulfilled by the NPT.

4.2.3 Description of the normalisation process theory

The NPT has four main concepts: coherence, cognitive engagement, collective action and reflexive monitoring, simply put these are roughly translated as investing meaning, engaging, doing and evaluating. Each concept is further subdivided into four sub-components which will be examined in more depth. For clarity in describing the NPT, the NPM, from which the NPT was developed, has
been incorporated into the description of the NPT, rather than being dealt with as a separate entity. This description is found in the collective action section of the NPT. The table below briefly introduces each component and sub-component of the theory and also the sub-components of collective action which were originally developed as the NPM. In order to present a fully formed description of the theory, further in depth discussion of the theory follows.
Table 4.1 Coherence, cognitive participation and sub-components

<table>
<thead>
<tr>
<th>Concept of the normalisation process theory</th>
<th>Sub-component of the normalisation process theory</th>
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<tbody>
<tr>
<td><strong>Coherence</strong>: describes and organises what must happen in order to bring new practices into being</td>
<td><em>Individual specification</em>: information gathering, developing personal sense of meaning</td>
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<td></td>
<td><em>Communal specification</em>: finding meaning in the intervention through group processes</td>
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<td></td>
<td><em>Differentiation</em>: a practice is defined by its difference from other practices</td>
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<td></td>
<td><em>Internalisation</em>: Meaning is internalised and allows the practice to form the experience of the individuals involved in undertaking the practice in an ongoing way.</td>
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<tr>
<td><strong>Cognitive Participation</strong>: Engagement and enrolment of individuals to prepare and position required people and resources for collective action</td>
<td><em>Enrolment</em>: Individuals working together and organising themselves to form a collective to put a new practice into action</td>
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<td></td>
<td><em>Initiation</em>: What must be done to make a practice work in context</td>
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<td></td>
<td><em>Legitimation</em>: Belief in practices and investing in the practice compared to alternative existing practices</td>
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<td></td>
<td><em>Activation</em>: Once it is underway, participants need to collectively define the actions and procedures needed to sustain a practice and to stay involved.</td>
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(May and Finch 2009)
Table 4.2: Collective action and related dimensions of the normalisation process model

<table>
<thead>
<tr>
<th>Concept of the normalisation process theory</th>
<th>Sub-component of the normalisation process theory</th>
<th>Dimension of the normalisation process model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collective action: the work which brings about new interventions</td>
<td>Interactional workability: Examines the impact of a new intervention on interactions both between people and practices</td>
<td>Congruence: what is achievable within interactions, what form the interaction takes, the role of the individuals involved in each interaction and how their roles and interactions are governed by both formal and informal rules.</td>
</tr>
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<td></td>
<td>Relational Integration: How the new intervention relates to existing relationships and knowledge</td>
<td>Disposal of work: the effects of interactions. What the goal is, where and when the outcomes should occur and how any disagreements about this should be minimised</td>
</tr>
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<td></td>
<td>Skill-set workability: How the existing division of labour is affected by a new intervention</td>
<td>Accountability: the knowledge and practices of those undertaking the intervention</td>
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<td></td>
<td>Contextual integration: How the new intervention relates to the existing context</td>
<td>Confidence: Beliefs about the knowledge and practices required by a complex intervention.</td>
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<td></td>
<td>Execution: Considers the practical implications of a new intervention such as availability and division of resources</td>
<td>Allocation: Division of labour and how decisions about the division of labour are made</td>
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<td></td>
<td>Realisation: Who is responsible for implementing a new intervention and does this result in a different distribution of labour?</td>
<td>Performance: Considers the capability of those undertaking the work of a new intervention to perform the allocated tasks</td>
</tr>
</tbody>
</table>

(May and Finch, 2009)
Table 4.3: Reflexive monitoring

<table>
<thead>
<tr>
<th>Concept of the normalisation process theory</th>
<th>Sub-component of the normalisation process theory</th>
</tr>
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<tbody>
<tr>
<td>Reflexive Monitoring:</td>
<td>Systemisation: The formalities of these evaluations and the rationale which forms them.</td>
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<td>Communal appraisal: Procedures put in place to formally evaluate the intervention in an ongoing way</td>
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<tr>
<td></td>
<td>Individual appraisal: Less systematic process of evaluating outcomes of an intervention and the contribution of the individual</td>
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<td></td>
<td>Reconfiguration: Where an intervention is not meeting expectations changes may be made</td>
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</table>

(May and Finch, 2009)

Tables 4.1, 4.2 and 4.3 above describe the NPT, the aim of the following section is to define these concepts further and look at how they interact and link together to result in normalisation or not.

4.2.3.1 Coherence

Coherence is when implementation begins, when actors undertake the work to develop ideas, beliefs and invest meaning in the new intervention. Communal specification describes how these ideas about the meaning and utility of the practice are shaped through shared understanding of what the practice is and what the practice means. In contrast individual specification is the work of understanding and investing meaning in the practice on an individual level, incorporates the complicated intellectual work of developing and understanding of how new practices exist alongside existing practices, beliefs and experience,
but also acts such as information seeking. The NPT identifies an important process of developing this understanding and meaning is realising the difference of the new practice to the old practices that the new practice seeks to either replace or with which the new practice will coexist, this process is described by the term differentiation. Having been developed this meaning is then internalised and allows for embedding as it becomes part of experience and in turn routine for those tasked with carrying out the practice.

4.2.3.2 Cognitive participation

Once shared meanings and understanding of a practice have been established the next stage in implementation is cognitive participation. This refers to both the “real and symbolic engagements and enrolments” that must be made to make collective action possible. The work to drive the first stages of implementation forward is termed initiation, without this work a practice would not be realised. Enrolment describes how people organise themselves to contribute to enacting the new practice. Finally legitimation is how those who must contribute to a new practice decide on the validity of the new practice and subsequently how this will affect engagement.

4.2.3.1 Collective action

Collective action is the most comprehensive component of the NPT having been developed originally as the Normalisation Process Model (May et al, 2007) which was eventually expanded to make the NPT. The original components of the NPM now form collective action which describes the material work of carrying out a practice. Collective action can be divided into immediate and organising factors. The immediate factors are interactional workability and relational integration and the organising factors are skill set workability and contextual integration. Each of these is then further subdivided into co-operative and executive dimensions.

How a new practice affects the interactions between individuals and organisations is described by interactional workability. The co-operative dimension of this factor is congruence which looks at the interaction itself. For example, the roles of the individuals, what the work is and how it is completed given the resources available. The executive dimension, disposal of work, looks at the results of the
interactions. For example the goals of the interaction and how these should be attained and when.

Relational integration, the second immediate factor, is concerned with how a new intervention relates to the knowledge already available and relationships between individuals and organisations already in place. Accountability relates to the knowledge and practices held by the individuals and organisations who will be involved in carrying out the intervention. Accountability deals with issues such as what knowledge is required, who holds this knowledge and what are the formal rules for distribution of knowledge and practice within the relevant organisations. Confidence concerns the beliefs that individuals and organisations hold about the knowledge and practice required to implement an intervention.

Skill set workability refers to how the work that must be undertaken in order to implement a practice is distributed and carried out. Contextual integration looks at how a new practice is incorporated in a social context. Allocation is how labour is divided between individuals and organisations and how resources are allocated. How an organisation can effectively implement practices related to a new intervention, such as training, is described by performance.

Contextual integration is concerned with the effects of implementing a new intervention on an organisation. Execution defines the practicalities associated with implementing a new intervention. Where responsibility lies for implementing a new intervention is described by realisation.

4.2.3.2.4 Reflexive monitoring

Finally, an important part to ongoing implementation work is reflexive monitoring which allows for assessment of the efficacy of the practice and how well it has been implemented both formally (communal appraisal) and informally (individual appraisal). Where required reconfiguration can occur to improve the practice, or how well the practice is implemented. Ongoing assessment is vital to maintaining normalisation.
The following diagram shows how each of these concepts interact with one another to describe how normalisation is brought about:

![Diagram of the Normalisation Process Theory](May and Finch, 2009)

**4.3 Application of the normalisation process theory**

The next section looks at how the NPT is being applied and how successful these applications have been. This section has been divided into four subsections each of which describe the process of using the NPT and present the findings of studies using both the NPM and the NPT to explore the benefits and difficulties of using the theory. The chapter follows the logical order of developing, evaluating and implementing interventions which is also the order used in the “trial killer” (Murray et al, 2010), named for how the paper describes the ability of the NPT to shut down a trial should it become clear that the intervention will not be
implemented. The “trial killer” paper which is where the descriptions of how to apply the NPT have been taken from.

4.3.1 Developing interventions using the NPT

While it may seem obvious, it is a vital observation in implementation science that an intervention is only effective if it is implemented. As stated above, implementation of interventions is the exception rather than the norm. With this in mind the NPT gives researchers a framework to consider implementation during the development of an intervention, and thereby improve the chances that an intervention will be implemented and eventually normalised.

One of the key strengths of the NPT is that it highlights potential contextual barriers to implementation, compared with more individualistic approaches such as the theory of planned behaviour (Ajzen, 1991). The context must render the implementation both necessary and possible. Murray and colleagues (2010) use the example of interventions to prevent smoking in public buildings becoming redundant in the context of laws which ban smoking in public places (assuming the law is followed and/or enforced), in this context the intervention becomes obsolete. Another example could be an expensive, multiplatform public health campaign to alert people to the dangers of an unusual injury. While this might prevent a few injuries a year the costs far outweigh the potential benefits especially in a system where public health resources are limited and other conditions effecting thousands, or even millions more people are vying for those resources. Aside from money, it would be hard to convince a GP to address avoiding this unusual injury during a consultation when he or she could be addressing smoking or alcohol consumption. In both these contexts the intervention becomes invalid.

These contextual issues are highlighted at each of the stages of the NPT, but most thoroughly at contextual integration in collective action where the theory asks how the intervention will fit with those practices already in place, and where there new intervention does not fit with existing practices, how this can be overcome. The context into which a healthcare intervention must fit is invariably complex, with other practices competing for resources such as time and money. Murray et
al give the example of the ImPACT back pain trial (Tooth et al, 2009) where the researchers discovered that in the context of a consultation back pain was rarely the primary complaint of the patient. As a result GPs did not place importance on discussing back pain and making referrals, this low coherence lead to low cognitive engagement and low participation.

Having defined the context, the next stage is to define the intervention. Relevant NPT concepts once again occur at each of the first three stages including differentiation, enrolment and skillset workability (the reflexive monitoring stage was purposefully omitted from this list as evaluation will be discussed in detail later in this chapter). The NPT sensitises the researcher to issues around how the intervention must be perceived as different from practices, while fitting with the current context and how the necessary people must be organised and trained in line with current roles and strengths.

Once both context and intervention are defined, an NPT evaluation of the intervention can take place. In the “trial killer” paper Murray and colleagues (2010) put forward a series of questions developed from the NPT to offer a framework to decide whether the new intervention is likely to be effectively normalised in the given context. These questions cover each of the concepts of the NPT. For example, a question to address differentiation from the concept of coherence is “Is the intervention clearly distinct from other interventions?” A question addressing contextual integration from the concept of collective action is “How compatible is it with existing practices?” To address these questions, a combination of the previous literature and primary data is likely to be required, in doing this the NPT can sensitise researchers to the requirements of new interventions if they are to become normalised in complex contexts such as primary care where the new intervention must both fit with current practices while being a distinct practice, and where people must be effectively engaged and remain engaged in order for the new intervention to compete effectively for resources and ultimately become normalised.

By using an NPT analysis during development of an intervention potential pitfalls can be identified and avoided to optimise the chances of uptake, or where these pitfalls cannot be overcome the intervention can be dropped prior to the start of
an expensive and time consuming trial. A third way is also possible, where interventions are redesigned using the NPT after initial failure to improve uptake as happened in the ImPACT trial (Tooth et al, 2009).

A second example of the NPT being employed during development of the intervention is the WISE (whole-systems informing self-managing engagement) approach to supporting self-care which consisted of a decision support tool Patient Report Informing Self-Management Support or PRISMs (Protheroe et al, 2010) and an information booklet both to be administered by nurses in primary care (Kennedy et al, 2010). The researchers developing WISE incorporated the NPT at development, evaluation and following implementation to assess uptake, but the use at the development stage is most novel. In order to optimise the chances of the WISE approach becoming routine care the researchers used the NPT to sensitise the approach to the conditions necessary for this to occur. This was translated as a continual process while developing the training materials to simplify the message and linked the materials to both the daily activities associated with enacting the intervention along with the overarching message of the WISE approach, thereby increasing coherence and preparing practices for cognitive engagement and collective action. By continually working with practices during development to ensure these materials were effective with the target group, reflexive monitoring was employed to maximise implementation.

While complex interventions are the focus of most discussion of the NPT, this type of analysis can be applied to new drugs or medical devices where the contextual barriers may not be obvious (Murray et al, 2010)

4.3.2 Using the NPT to evaluate an intervention

The second application of the NPT is in evaluating the intervention. This is not to say that the NPT replaces standard evaluation methods such as randomised controlled trials, but that NPT analysis can be used as part of a trial to optimise the evaluation. Trials often focus on the efficacy of the intervention without consideration for how that intervention will fit into the context in which it will eventually be implemented in order to be effective outside the trial circumstances. With this in mind defining the context is the first step in undertaking an NPT analysis as part of a trial (Murray et al, 2010). Researchers must ask questions
about where, how and who will be undertaking the work associated with implementation and carrying out tasks associated with the intervention. How will this work fit with current practices and resources?

Once the context has been established, researchers must define the trial and those affected by the trial. As Murray et al report, the introduction of the CONSORT statement (Begg, 1996; Altman, 1996) to regulate clinical trials demands the consideration of context, but guidance for how to do this is limited, this is where the NPT can become very useful to researchers developing interventions with the focus the theory places on contextual issues. The advantage of employing the NPT alongside the prescriptive CONSORT statement is that the NPT sensitises the researcher to the impact of the trial on the work already in place of those who are undertaking the work of the trial.

Having defined the context, trial parameters and actors the NPT analysis can take place. Murray et al use an example which shows that, by following the NPT framework, researchers are sensitised to the importance that all trial participants have to find the trial meaningful (have high coherence) in order for cognitive participation and collective action to follow and ultimately for the implementation of intervention. It is easy to see, using the NPT framework, that if participants are not convinced of the efficacy of an intervention (have low coherence) then they are less likely to undertake both the organisational work and practices which must happen for implementation to occur. Establishing coherence and similar social and contextual hurdles can be lost amidst the prescriptive guidelines set out for undertaking a success trial, by highlighting these potential issues researchers can design trials to reduce dropout rates in trials.

An example of the NPM in use alongside standard evaluation methods is this process evaluation was completed as part of an exploratory randomised controlled trial of collaborative care for depression which impacts both at patient and at professional level. Gask et al (2010) used an NPM framework and their study is notable because it contains data collected before implementation which allows for some evidence towards the predictive value of the NPM.

The authors conducted interviews with patients and practitioners and focus groups before and after the trial. The data collected before was to assess the
predictive value of the NPM while the data collected after could be used if any revisions to the intervention were required. The authors were particularly interested in using the NPM to uncover hidden work which stakeholders may have to undertake in order for the intervention to be implemented. Through pre-trial interviews with stakeholders they found that much of the hidden work was identified, thereby showing that using the NPM may have sensitised the researchers to this work. Once again, using the NPM to analyse qualitative data, more hidden work was discovered following the trial which could not have been predicted. The authors report that the NPM provided a rich framework for analysis and considering implementation. However, it is unclear if other analysis strategies would have yielded the same results.

Where it becomes apparent through the NPT analysis that there is too low coherence, too much additional work to fit with the context of the trial or other pitfalls listed above, there is an opportunity to redevelop or amend the trial. If this is either unsuccessful or not possible due to resources or other limitations then the NPT can once again act as a “trial killer” (Murray et al, 2010). In other words, the analysis can indicate that a trial is unlikely to succeed and is therefore undertaking the trial is not a valid use limited resources.

4.3.3 Using the normalisation process theory during implementation

The NPT can be used once again when the intervention is finally implemented. Implementation is often carried out by people who were not involved in either designing or trialling the intervention, in this case the information concerning the contexts in which the intervention was both developed and evaluated should be obtained where possible (Murray et al, 2010). The similarities and differences of these contexts need to be considered, for example many trials include added support for those health care professionals delivering the intervention. How do these differ from the contexts in which the intervention must ultimately be implemented?

Once again, the intervention must be defined much like during the analysis which may have been conducted at the development stage, although the intervention may be different at this late stage (Murray, 2010).
With these two definitions in place then NPT analysis can go forward and can sensitise those responsible for implementation to pitfalls from coherence through to reflexive monitoring, such as acceptance of the new intervention from all those associated with delivering the intervention as well as those who will receive it (Murray et al 2010). As with the uses defined above, the advantages of the NPT analysis is that social and contextual issues are highlighted during implementation, helping to ensure that an intervention doesn’t fail to be taken up because issues around work, understanding and resources have not been taking into account.

Researchers who have applied the NPT to examine the process of implementation are positive about the theory in this context (McEvoy et al, 2014). The following research is organised to show how the NPT is being applied to implementation and the evidence for the usefulness of each NPT concept. There is overlap between the concepts, this can be a problem with applying the NPT and some researchers have reported difficulty in discerning the differences between concepts (Atkins et al, 2011; Franx et al, 2012 in McEvoy et al, 2014).

4.3.3.1 Coherence

The NPT literature on applying coherence focussing on the understanding and conceptualisation of interventions and the work involved (McEvoy et al, 2014).

A study looking at why tele care systems as a means of support for self-management are not becoming implemented used the NPT to evaluate why this might be (May et al, 2011). This was a large-scale study which incorporated a variety of different stakeholders. These included health and social care professionals, patients, carers and manufacturers of the tele care systems. The authors summarise that the lack of coherence between policy and practice and this prevents the uptake and eventual implementation of tele care systems. That those devising the interventions should take into account the current self-care strategies of people they hope to use their systems. They conclude that more resources to implement tele care systems may not be the way to normalise tele care system usage but to increase the understanding of how tele care systems change the work and workload of service users both patient and professional.
As stated many times throughout the chapter, considering the context in which the intervention will be placed is vital to the NPT description of implementation. This study examines how practices, rather than GPs, implement depression care (Gunn et al, 2010). Depression work requires boundaries of what constitutes depression and, as an extension, who is identified as suffering from depression. In order for an intervention to be embedded in routine, all the people, organisations and technologies involved must have a shared meaning of what depression means and what depression work entails. The authors found that depression was seen as a complex area to categorise due to the interactions between social, practical and psychological issues which contribute to the condition. This leads to difficulties forming a shared understanding of what depression is. In all there was a lack of shared understanding, or coherence, around depression and depression work which acted as a barrier for implementation.

The work of Bamford et al (2012) demonstrates the importance of the coherence dimension. In this study about implementing evidence-based dietary changes in residential care homes for the elderly, the authors found that coherence was the key factor to establishing implementation. In this study where care workers did not place meaning on the intervention, in placing their own knowledge and beliefs about the context in which the intervention would be implemented above the evidenced based intervention. The care workers did not engage with the implementation, legitimacy was in question and initiation did not occur in line with the low coherence, in some cases chefs felt devalued by the intervention resulting in low enrolment. Ultimately this resistance played out as refusing the work of organising or undertaking the practices. As a result, implementation did not occur and was evaluated as a failure in a “self-fulfilling prophecy”. In this case it is interesting to note that low coherence was not solely about the health benefits of the intervention, but meaning attributed to contextual factors including perceived quality of meals, the relationship between care giver and resident, and the lack of meaning attributed to health policy in general as it regards residential homes. In order to implement this intervention a greater meaning must be attributed to serving these healthier meals than all of the above and in some cases this did not happen.
The current literature examining the role of coherence in implementation shows that where stakeholders do not understand or value on the practices involved this acts as a barrier to implementation.

4.3.3.2 Cognitive participation

The emphasis of previous literature on cognitive participation emphasises the importance of legitimation and buying in to the practice (McEvoy et al, 2014)

Depression work requires the people involved to engage with a shared set of techniques to manage depression (Gunn et al, 2010). Cognitive participation requires the health care professionals as well as the patient and their network members to actively engage with depression work. An interesting finding is that GPs reported where patients did not engage with either the treatment or accept the condition, and as a result did not engage with the treatment, then treatment could not work. While this is not a surprise, it shows the importance of the patient engagement in the implementation of interventions. The authors conclude that at the time of writing, there was limited agreement and engagement with shared ideas about the practice team skill set required for depression care.

4.3.3.3 Collective action

The concept of collective action accounts for a lot of the current NPT and NPM literature (McEvoy et al, 2014). This is because the NPM, from which the NPT was developed, became the concept of collective action. When the NPM was originally developed (May, 2007) it presented a framework to use the NPM for process evaluations of randomised controlled trials.

The existing work on collective action has been broader than the other concepts, reflecting the larger body of work. This work examines how the interventions fit into the contexts, who will undertake the work, who has the skills to do the work and their confidence to be able to do so, and organisational effects (McEvoy et al, 2014)

A paper comparing implementation of two interventions with clinically significant outcomes in randomised controlled trials (May, 2007). The first is
management of chronic heart failure, the second is improvement of problem solving therapy for people with depression. Both interventions take place in primary care but were chosen because they were likely to suffer different barriers to implementation. The study begins by looking at the interactional workability of the interventions. As described above interactional workability (see table 4.2) defines the immediate contexts which practices associated with the intervention is being integrated into.

With problem solving therapy congruence between professionals and patients seemed high with both groups wanting psychological, rather than pharmacological treatments. However, this was not reflected in treatment uptake. Which suggests that, in practice, congruence was incomplete and meant that in some cases effective disposal was unlikely. New interventions are unlikely to become implemented if they do show an interactional advantage and in turn facilitate disposal of work. The chronic heart failure was nurse led self-care support, the intervention fit in with current contexts in that patients are used to, and happy with nurse led chronic care management, this also yields positive outcomes. However, the authors found a lack of congruence between health care professionals and patients about the significance of chronic heart failure. This could affect disposal as the nurse had to spend some time establishing shared meaning with the patients.

The value of applying the NPM is that this framework allowed for the identification of hidden work around relational integration in both studies. The use here exposed health care professionals having to deal with and dispose of patient's problems as well as implement the intervention in hand. The study highlights the importance of the allocation of work and related skillset workability which was clearly defined in the heart failure study, but the psychological therapies study showed confusion over who would deliver the intervention and resultant complications with skillset workability.

The following process evaluation mental health interventions in primary care also found that where skillset workability is not in place and contextual integration is not possible implementation becomes unlikely (Gask et al, 2008). The authors applied a NPM framework with focus on skillset workability and contextual
integration to look at organisational efforts to implement mental health care in primary care. GPs felt they either did not have the skills to treat people with mental health needs, nor did they know what their role was in treatment resulting in a barrier to carrying out practices. In terms of contextual integration the authors found persistent instability of the organisations and identity, personnel and strategic direction impacting on normalisation of new practices. One of the key findings of this evaluation from the point of view of this review is the authors found “a lack of shared knowledge or understanding of their role in improving the quality of mental health care within primary care” acted as a barrier to normalisation which adds weight to the inclusion of coherence in the NPT.

A study examining implementation of e-health devices concludes that the NPT concept of collective action described the processes associated with implementing new healthcare interventions (Murray et al, 2011). This study examined the implementation of three e-health interventions. The study found that interventions in the study that impeded interactional workability, relational integration or contextual integration would be less likely to become normalised. Those that fit with the current skillset (skillset workability) were more likely to become implemented. Adding to the body of evidence supporting the NPT as a theory.

The evaluation in the implementation of the WISE approach discussed above (see 2.2.6 and 4.3.1) supports the NPT by showing the barriers which can occur at collective action even when coherence is high (Kennedy et al, 2014). Coherence was high with the nurses who saw improving self-management support as meaningful when working with people with long term conditions and they were engaged with the practice, but problems occurred with barriers to actually enacting the practices at the collective action stage. Barriers occurred with both contextual integration and relational integration. In primary care there are always practices competing for limited resources, new practices which are introduced into this context must either fit easily fit with existing practices or de-normalise practices already in place, in the case of new interventions relating to the care of people with long term conditions the new intervention will have to fit into the context of formalised care programmes prescribed by the Quality and Outcomes Framework (QOF) which requires nurses to take certain specific measurements.
during consultations (NICE, 2009). With QOF checks already normalised, using the limited time of the consultation and also monitored, evaluated and reinforced with performance based pay, any new practices must fit around these checks. This is a part of the reason the PRISMs shared decision making tool aspect of the WISE approach failed to normalise in practice, it simply took too long to enact the intervention and could not compete in the context of the consultation. The second difficulty that those attempting to implement PRISMs came up against was one of relational integration and the problems of introducing shared decision making tools into the traditionally didactic relationship between nurse and patient. In line with the previous findings regarding implementation of shared decision making tools (Elwyn et al, 2008) the partnership associated with using the PRISMs tool was found to be too disruptive to the nurse-patient relationship, denormalisation of the existing power dynamic would have to occur for the normalisation of the more balanced relationship required to undertake the work required to use PRISMs.

In applying an NPM framework to examine the failure of shared decision making technology the implement the authors found the benefits of the NPM over other theory, or a priori analysis was that rather than highlighting “many barriers” they were able to establish areas for concentrated efforts, which before were not considered, which if targeted may lead to normalisation (Elwyn et al, 2008).

The use of the NPT identified barriers where there is uncertainty reported around allocation of work, if anything should change, who would take on the work and what work could be allocated to nurses or receptionists (Gunn et al, 2010). Nurses were concerned about their skill set in dealing with people with depression. As well as internal skills, the practice members have to keep up with policy and the government is needed to facilitate communication within organisations, between organisations and with patients.

This collection of the studies applying the NPM or collective action demonstrates that the concepts do identify barriers to implementation when applied. More importantly in the context of this study, the studies cited demonstrate the ability of the theory to identify hidden work and the ability of the theory to identify particular areas for targeted efforts.
4.3.3 Reflexive monitoring

Where the system of reporting was not joined up or standardised meant that reflexive monitoring was difficult for those involved in depression work (Gunn et al, 2010). Once again in this study the authors report finding that the NPT provided a rich framework to study existing practices with a robust study design. The studies cited here report that the NPT or NPM was a valuable tool to facilitate understanding of why certain types of intervention do not become embedded in practice. This is supported by the findings of another review of the NPT literature (McEvoy et al, 2014)

4.3.3.5 Summary

This is not an exhaustive review of all studies employing the NPT but designed to present a representative sample of work to show how researchers are using the NPT (and NPM) and how effective the theory has been in these cases. In each case presented in this chapter the researchers found value in employing an NPM or NPT framework, at various times they have reported that low coherence (Bamford et al, 2012; May et al, 2011), low cognitive engagement (Gunn et al, 2010), and hidden work or contextual barriers affecting collective action (Murray et al, 2011; May et al, 2007; Elwyn, 2008; Kennedy et al, 2014) and to a lesser extent negative evaluation (Gunn et al, 2010) have negatively impacted on implementation. From the evidence presented through use of the NPT the theory accomplishes the first and second of the requirements of a theory outlined by May (http://www.normalizationprocess.org/theory-behind-npt/what-is-a-theory.aspx), accurately describing and explaining the processes by which implementation occurs (or does not occur) is the strength of the NPT. In particular the emphasising the social and contextual process which can be missed by traditional, individualistic theories of behaviour change.
The third requirement is more difficult to assess as the theory has not really been challenged in these aspects, whether the NPT can successfully explain and predict implementation should become clearer with the development and introduction of an NPT measurement (Finch et al, 2013).

4.3.4 Criticism of the normalisation process theory

On assessing the ability of the NPT to predict implementation one must define what is meant by predict. As stated by Lempert (2010) “social scientists are not physicists, and people are much harder to understand than even questionably existent subatomic particles”. He goes on to question whether social science theory can claim predictive value when the subject of the theories have “minds of their own” and behave in unexpected ways. May (2013) counters that while it may be unlikely that any theory from the social sciences can achieve the requirements which Lampert would place on them predictions can be made in broad terms about the course that events may take and that by setting out the mechanisms at work and specifying how these work possible outcomes can be predicted. Whether the NPT will achieve this is still unknown, using the NPM can indeed uncover hidden work that may have acted as a barrier to implementation (Gask et al, 2010). In contrast to this, where the NPT was employed while developing a new intervention, as in the WISE approach (Kennedy et al, 2014), to sensitise the researchers to issues surrounding implementation, using the NPT at development did not result in successful implementation. The introduction of a measurement will produce more conclusive evidence in the future.

Ultimately, what can be said of the NPT from the literature presented here is that it cannot be concluded that a priori application of the NPT maximises the potential of interventions. What is clear is that researchers find using the NPT sensitises a posteriori analysis of implementation processes to otherwise hidden processes.
4.3.5 Applying the Normalisation Process Theory to Individuals

The secondary aim of this thesis is to look at how the NPT can be used to provide a framework through which to examine the experiences of people with diabetes. Having established the value of using the theory. In particular how the researcher is sensitised to the social and contextual processes in the data, which are often overlooked by behaviour change theory focussed on the individual, we can consider applying the theory to the implementation of self-management practices. Here NPT may help to identify hidden work that has to be undertaken by the individual and those in the social network of those people with diabetes. Using the NPT in this novel way may help to identify previously overlooked barriers to self-management for people with type II diabetes.

At the time the research for this thesis began, the NPT hadn't been applied to individuals only to organisations, since then one paper has been published looking at applying an NPT framework to understand treatment burden on people with chronic heart failure (Gallacher et al, 2011). This paper looked at similar self-management practices to those associated with diabetes self-management, the authors applied a framework developed from the NPT to data that had already been collected to look at patient's knowledge, understanding and experiences of living with chronic heart failure. Table 4.4 shows the framework applied in this study.
Table 4.4 Framework employed to explore treatment burden experienced by people with chronic heart failure

<table>
<thead>
<tr>
<th>Coherence (Sense-making work)</th>
<th>Cognitive Participation (Relationship work)</th>
<th>Collective Action (Enacting work)</th>
<th>Reflexive Monitoring (Appraisal work)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Differentiation: Defining, dividing up, and categorizing task</td>
<td>Enrolement: recruiting the self and others to tasks</td>
<td>Skill set workability: allocating tasks and performances</td>
<td>Reconfiguration: changing tasks</td>
</tr>
<tr>
<td>Communal specification: making sense of shared versions of tasks</td>
<td>Activation: organizing a shared contribution to tasks</td>
<td>Contextual integration: supporting and resourcing tasks in their social contexts</td>
<td>Communal appraisal: shared evaluation of contributions and tasks</td>
</tr>
<tr>
<td>Individual specification: making sense of personal versions of tasks</td>
<td>Initiation: organizing an individual contribution to tasks</td>
<td>Interactional workability: doing tasks, and making outcomes, in practice</td>
<td>Individual appraisal: individual evaluation of contributions and tasks</td>
</tr>
<tr>
<td>Internalization: learning how to do tasks in context</td>
<td>Legitimation: making tasks the right thing to do</td>
<td>Relational integration: making and communicating reliable knowledge about tasks</td>
<td>Systematization organizing: a reliable stock of knowledge about tasks</td>
</tr>
</tbody>
</table>

(Gallacher et al, 2011)

The authors applied this framework and themes which fell outside the framework were examined to see if the concepts were failing to address all relevant issues. Gallacher and colleagues (2011) report that they found that the NPT provided a solid framework for looking at the experiences of treatment burden by people with chronic heart failure.

The authors found that the burden of managing chronic heart failure spread across the four concepts of the NPT. However, they also report that some aspects of emotional work did not fit neatly into the NPT, these included spiritual thoughts and anxieties about death. The authors state that there are quality of life
instruments which could be used to assess these aspects. On the other hand, minor modifications to the concept of coherence or one of the facets of coherence could potentially be made to the theory to encompass these aspects, making the NPT more appropriate for looking at individuals. The study contained in this thesis should give greater insight into how this might be achieved. The fact that Gallacher and colleagues (2011) reanalysed existing data means some aspects of treatment burden may have been missed as the original interviews did not seek to explore treatment burden rather patient perceptions, understanding and knowledge.

4.3.5 Summary

Despite being conducted with a similar population as the previous study, the study within this thesis builds on the work of Gallacher et al (2011) in several ways. The first is by using primary data which allows for interviews focussed on the research question and also by allowing for the usual iterative analysis associated qualitative research. The constant comparison method used in this study will also allow for emerging themes to be examined with greater depth in later interviews. This study also framed the research question to look at a wider range of practices associated with self-management and with the notion of embedding as an ultimate aim providing a more comprehensive view.
5 Methodology

5.1 Introduction

The aim of this chapter is to describe, discuss and critique the research methods used to address the research questions central to the study. There have been many changes between the original thesis plan and the methods which were finally used. Some of these changes focused the research more clearly on the thesis aims, such as streamlining the study by dropping the quantitative component of the study. Others were arrived following increased knowledge and experience in qualitative research, for example changes to the analysis strategy. Each change has been a learning opportunity; this chapter will explain how the ultimate method for the thesis came about with clarity and transparency, other options that were considered throughout the design and development are discussed in and each case the reason for rejection is made explicit.

This study is nested in a larger National Institute for Health Research Collaboration for Leadership and Applied Health Research and Care (CLAHRC) funded programme of work which aims to develop new interventions to support self-management in people with long term conditions. The methods for the CLAHRC study are also discussed briefly in so far as they have relevance to the aims and focus of this thesis.

5.1.2 Aims and Objectives

The findings of the literature review in chapter three identified the need for more information on what can prevent people with type II diabetes from embedding self-management practices into their everyday life.

5.1.2.1 Study aims:

- To contribute to the understanding of barriers to self-management in type II diabetes.
- To assess whether the NPT is appropriate for using in studies which examine individuals operating in open systems.
5.1.2.2 The objectives of this study are as follows:

- To identify barriers to self-management experienced by people with type II diabetes in Greater Manchester and the surrounding area.
- To assess whether the NPT is helpful in the interpretation of a study of type II diabetes self-management in individuals operating in open systems.

5.1.3 Study design

5.1.3.1 Methodological approach

The methodological approach used must be the most appropriate to answer the research questions within the constraints of the study, such as the time available and the financial costs of fieldwork. Qualitative research methods for health services research address the “what”, “how” and “why” questions rather than “how many” questions generally addressed by quantitative research (Green and Thorogood, 2004). Discovering and examining barriers experienced by people falls into the first three of these categories, rather than questions more appropriately answered by quantitative methods.

Data from qualitative methods, such as the semi structured interviews used in this study, provides insight into how the study participants understand and interpret their social reality (Bryman, 1988) in order to identify barriers which fall outside of medically focussed parameters. Interviews allow for investigation into how participants choose self-management practices, how these practices fit into their everyday routine, what happens if the practice does not fit into the routine of the participant and why this happens.

5.1.3.2 Initial Study Design

Originally this study was going to be conducted as a two phase study using both quantitative and qualitative methods. The quantitative phase was due to take place prior to the qualitative phase in 2010-11, which was the second year of the proposed three year timescale. The planned qualitative analysis would have been used as one of the factors that would inform the interview schedule for the qualitative phase, which would have been an unconventional timetable. The reason for this is that the survey study had already been designed and was in the
process of being administered by the CLAHRC team. Specifically, sections B, C and D of the questionnaire relating to illness perceptions (Broadbent et al, 2006; Leventhal, 2003), health status, and self-efficacy (Osbourne, 2007) along with the measure of normalisation developed for the survey. These sections were chosen because they related to the barriers identified as important as part of the initial literature search conducted at the conception of this study. It was intended that the most recent HbA1c level of each participant would also to be obtained, with the consent of the participant, from their GP. Using statistical methods scores for each of the scales would be used to look for relationships between each scale with the HbA1c level and normalisation score separately. The NPT was important to the background of the CLAHRC study (see chapter 2.2.5); a normalisation score was developed by the CLARHC team and included in the CLAHRC study. The normalisation score would also be tested for relationship to the HbA1c level for each participant. Over time the study became focussed on the qualitative work until, finally the quantitative section was removed entirely. Qualitative methods suited the exploratory nature of the research primary research question, to identify barriers to self-management, better than picking data from a large survey not designed to address the specific research question. This is in line with Green and Thorogood’s criteria, the quantitative component would not have addressed the “what” and “why” questions central to answering the primary research question.

5.1.3.3 Benefits of Qualitative Methods to Address Research Questions

That qualitative research allows for collection of detailed data about how people understand their social world is vital for the exploratory approach that is required to address the primary research question of this study, which is to identify barriers to self-management experienced by people with type II diabetes. To do such a wide ranging exploratory study using quantitative methods would be open to problems associated with multiple significance testing, including testing so many variables that it can potentially produce false positives (Bland, 2000). Another disadvantage of using a quantitative approach such a survey is that it would require prior insight to construct a survey (Bowling, 2005). While research has been conducted giving some of the insights needed, a survey study would run the risk of missing important barriers. Quantitative methods would be more
appropriate in a follow up survey study, which would test the findings of the qualitative study and be more generalisable due to using a larger sample. Table 5.1 outlines the characteristics of qualitative research as described by Ritchie and Lewis (2003) and looks at how these are addressed in this study.

**Table 5.1: Characteristics of qualitative research and how each characteristic is addressed in this study**

<table>
<thead>
<tr>
<th>Characteristic of qualitative research</th>
<th>How the characteristic was addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aims to provide an in-depth understanding of the participant’s social world by examining their circumstances, experiences, perspectives and histories</td>
<td>Interviews were used so that participants could fully explain their circumstances, experiences, perspectives and histories, highlighting and focusing on what is important to the participant</td>
</tr>
<tr>
<td>Small samples of participants who have been sampled purposively based on relevant criteria</td>
<td>A sampling strategy was devised through conducting a review of relevant literature to achieve a varied sample. This was reviewed during the study</td>
</tr>
<tr>
<td>Often data collection methods are interactive between the researcher(s) and participants(s) which are flexible and allow for the exploration of emergent issues</td>
<td>Semi structured interviews were employed so that the researcher and participant could interact and explore issues important to the participant</td>
</tr>
<tr>
<td>Data produced are extensive, greatly detailed and rich in information</td>
<td>The interviews produced rich and detailed data</td>
</tr>
<tr>
<td>Analysis is open to emergent concepts which may produce description, identify patterns of association or develop typologies</td>
<td>The framework analysis approach used aimed to fully describe and identify patterns in the data</td>
</tr>
<tr>
<td>Outputs often focus on finding meaning through mapping and representing the social world of the participant</td>
<td>The final step of the framework analysis process involves mapping and drawing conclusions from the data</td>
</tr>
</tbody>
</table>

(Ritchie and Lewis, 2003)
5.1.3.3 Data Collection

5.1.3.3.1 Interviews or Focus Groups

Two main methods of primary data collection were considered to explore how individuals experience the world; interviews and focus groups. Generally, for health services research, interviews are conducted between the interviewer and a single participant using open ended questions that are semi structured (Carter and Henderson, 2005). The advantage of this method is that the data collected is very rich in nature and allows for the study of the range and complexity of ideas relating to implementing practices (Murphy et al, 1998). Topics can be both guided by the interviewer and allow for the participant to include issues that may not have been previously considered or to expand issues they find particularly important (Britten, 1995). Focus groups involve a researcher asking questions to a group of participants rather than individually, using focus groups allows for an insight into health decision making in a social context (Kitzinger, 1994). This may have been useful in establishing the barriers but potentially would have resulted in a loss of depth in the data and especially in understanding how each participant experiences their social world (Carter and Henderson, 2005). The data collected from focus groups would have been different, dynamics between people may have presented themselves if social groups were interviewed together, but at the same time this could have inhibited the participants at the centre of the group from speaking honestly about how the group impacts on their self-management. The voices of quieter people can be lost in focus groups, resulting in extra weight being given to data from more dominant participants, although this can be tackled during interviews (Finch and Lewis, 2003). Conversely, safety in numbers can give people confidence to participate (Lederman, 1983). Researcher inexperience may have also made a focus group study inadequate as the researcher would be responsible for managing the group and facilitating the discussion.

5.1.3.3.2 Case Study

An alternative strategy for data collection was considered because there were concerns about the richness of the data coming from the phase one interviews. In this strategy, a small number of cases would have been studied in more depth by
interviewing key members within the social network, to ascertain different perspectives on how the network facilitates and supports self-management as well as how members may act as a barrier to self-management. The reason for considering a case study design to improve the study was that lots of participants were reporting that they took sole responsibility for managing their condition. By adopting a case study design, different perspectives could be accessed giving a more holistic picture of the social context surrounding self-management practices (Bryman, 2001). However, the case study design was rejected for several reasons:

- The first is that data collection for the study began well into the allotted research time and after the pilot and phase one interviews time was a pressing concern. Various study design features would have to be amended or completely redesigned. The sampling strategy would have to be redesigned to accommodate the smaller sample, ethical permission to approach families and other social network members would need to be obtained from the relevant bodies. Furthermore consent would have to be given by each participant selected to contact their social network members. Decisions would have to be made about how many network members would be interviewed per case and which members could be considered key members. These decisions would have to be thoroughly researched, resulting in another delay in the progression of the study.

- Secondly, analysis would be more complicated, for example how much weight is given to each interviewee during analysis? How would comparisons be made between network members? Between participants or between groups of participants across cases? (Ritchie and Lewis, 2003). As this is the first qualitative study conducted by the author this might have been outside the capabilities.

- Finally, improvements to the interview schedule and technique addressed the concerns about the richness of the data. Using fewer, less direct questions along with improvised probing, follow up questions seemed to make participants less defensive and more likely to divulge when and how
they receive assistance. The development of the interview schedule and technique is discussed in section 5.2.4 of this chapter.

5.1.3.4 Analytical Approach

5.1.3.4.1 Considering Analytical Options

Various approaches to analyse data from interviews are available to researchers, together these are referred to as content analysis and involve systematically working through transcripts, applying codes to individual quotes to identify patterns, similarities and differences throughout the data set (Donovan and Sanders, 2005). These approaches include both inductive and deductive methods of coding data with varying degrees of a priori theory.

Two content analysis methods were considered and tried before deciding on framework analysis. In the original proposal, grounded theory (Glaser and Strauss, 1967) was considered as a potential analysis strategy. However, there are considerations that quickly made it clear that grounded theory would be an inappropriate analysis method, particularly the assumption that a researcher can approach data without preconceptions and biases (Corbin and Glaser, 1990). The a priori nature of the grounded theory approach is particularly problematic for this study which intended to use a theory to extract meaning from the data, not only this but it would also be ineffective to address the secondary aim of the study which is to assess the NPT for use with individual actions.

Another approach to discourse analysis is thematic analysis: once again the researcher codes the data freely, but when using this method background knowledge and theory are acknowledged (Joffe and Yardley, 2004). Thematic analysis was considered for use in this study, but using a free coding thematic analysis strategy did not facilitate the application of the NPT to the data.
5.1.3.4.2 Framework Analysis

Framework analysis was designed in the context of conducting applied qualitative research such as this study. Questions addressed by this type of research fall into four broad categories listed in Box 5.1:

<table>
<thead>
<tr>
<th>Box 5.1: Categories of questions addressed by framework analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Contextual: identifying the form and nature of what exists</td>
</tr>
<tr>
<td>• Diagnostic: examining the reasons for and the causes of what exists</td>
</tr>
<tr>
<td>• Evaluative: appraising the effectiveness of what exists</td>
</tr>
<tr>
<td>• Strategic: identifying new theories, policies, plans or actions</td>
</tr>
</tbody>
</table>

(Ritchie and Lewis, 2003)

The primary aim of this study, to identify barriers to self-management, requires asking questions that are contextual, diagnostic and evaluative to give a holistic reflection of the experiences of participants. The use of the framework allowed for the application of the normalisation process theory to the data, the first advantage of which is to sensitise the researcher to relevant processes and issues that may be missed using a more inductive approach (Layder, 1998). The second advantage of using a framework developed from the NPT is that themes falling outside of the theory might be expected to be identified contributing to answering the second research question which is to evaluate the adequacy of applying the NPT to the practices of people operating in open systems.

The framework method is more prescriptive than other forms of thematic analysis, this has its advantages and disadvantages (Donovan and Sanders, 2005). Framework analysis is relatively easy to undertake (Donovan and Sanders, 2005), in the case of the current study the prescriptive nature of framework analysis works in favour of the author who has little experience in working with qualitative data. The method facilitates analysis under time constraints (Ritchie and Spencer, 1994; Donovan and Sanders, 2005). There are some concerns that where guidelines are too rigid analysis can become inflexible (Braun and Clark,
Recording themes that fall outside the framework safeguards against inflexibility resulting in loss of data. There is also a risk that those researchers inexperienced with qualitative research can interpret the data from the matrixes in the mapping stage as similar to quantitative data and holding similar meaning (Gale et al, 2013). This risk was kept in mind during analysis to avoid reporting findings inappropriately, for example rates that themes appeared were not counted. Box 5.2 outlines the five stages of framework analysis

Box 5.2: Five stages of framework analysis

- Familiarization: immersion in data, identifying themes, overview of issues
- Identification of the thematic framework: identifying key concepts and themes from research questions and emerging from data
- Indexing: applying coding framework
- Charting: producing a picture of the data by abstracting themes, using headings from the framework.
- Mapping and interpretation: description of findings, developing typologies, explanations, concepts and associations

(Ritchie and Spencer, 2003)

5.1.3.5 Previous Application of the Normalisation Process Theory to Data Relating to Individuals

Prior to me undertaking the analysis of these data, the NPT had been to the experience of individuals once before (Gallacher et al, 2011). The NPT was framework developed from the theory then applied to interview data collected as part of another study (see 4.3.5). The authors developed a framework directly from May and Finch’s 2009 paper describing the normalisation process theory, with illustrative text to show how each of the theory constructs related to their question about treatment burden experienced by people with coronary heart failure. They followed the five stages of framework analysis outlined above and recorded any codes that fell outside the framework. The study reported that the theory was fit for purpose using this framework approach, although they noted
that emotional and spiritual issues fell outside the framework and therefore were not covered by the theory, those themes that did not fit were dismissed in the paper and little mention is made of them.

5.1.4 Quality Considerations

Quality in research methods has been a key concern throughout the study and was always considered when making decisions regarding data collection and analysis. Qualitative research is particular affected by researcher bias, which is inherent in data collection and coding schemes (Murphy et al, 1998). This does not mean that there cannot be criteria for quality in qualitative research, in fact rigor is just as important as in quantitative research, to ensure that research is meaningful. It is important to be explicit in describing the research process, so as to ensure transparency and the potential for replication (Murphy et al, 1998). There have been various attempts to develop checklists to ensure quality in qualitative research (e.g. Hammersley, 1990; Tong, Sainsbury and Craig, 2007), which are subject to debate (Barbour, 2001). For the purposes of illustration, I have used the criteria laid out by Mays and Pope (2000) to demonstrate how quality was addressed throughout this study (Table 5.2)
Table 5.2 Quality considerations in qualitative research

<table>
<thead>
<tr>
<th>Quality requirement</th>
<th>Description</th>
<th>How requirement was addressed in this study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Triangulation</td>
<td>Data should come from two or more data sources; this can either be a combination of data collection methods or collecting data from different interest groups. The research can then look for patterns of convergence.</td>
<td>The use of purposive sampling ensured that a variety of people were included in the study.</td>
</tr>
<tr>
<td>Respondent validation</td>
<td>Also known as member checking, respondent validation involves checking that the researcher’s findings correspond to the participants’ accounts. These findings are built into the study results.</td>
<td>Due to time limitations it was not possible to obtain participant comments on findings. If there was more time then follow up interviews after results had been formulated would be possible as participants consented to future contact on this project.</td>
</tr>
<tr>
<td>Clear exposition of methods of data collection and analysis</td>
<td>Because the research and analysis method influences the data and how it is interpreted it is important to keep a clear record of what was done and why.</td>
<td>This chapter aims to give a comprehensive account of each stage of the study design and conduct. As well as this copious notes were taken in reflective diaries during data collection and analysis.</td>
</tr>
<tr>
<td>Reflexivity</td>
<td>Researchers must be sensitive to the affect that personal and intellectual biases have on data and analysis. These need to be made plain from the outset.</td>
<td>Researcher bias has been carefully considered and acknowledge throughout design, data collection and analysis. Transparency has been maintained throughout the relevant sections of this thesis including but not limited to the methods, results and discussion chapters.</td>
</tr>
<tr>
<td>Attention to negative cases</td>
<td>Cases which do not conform to, or contradict the emerging theory must</td>
<td>One of the strategies employed throughout analysis was paying attention to those cases, or themes that did not fit with</td>
</tr>
</tbody>
</table>

93
Having described the considerations taken into account when designing this study, the next section will go on to explain how the study was carried out.

5.2 Methods

5.2.1 Collaborations for Leadership in Applied Health Research and Care

This study has been completed as part of a large, National Institute for Health Research funded Collaboration for Leadership in Applied Health Research and Care (CLAHRC) programme of work with the ultimate aim of increasing access to care for people with long term conditions (Rogers et al, 2011). In order to address the aims of the CLAHRC study, the CLAHRC study was split into several phases. The first phase was data collection and can be split into two parts: the first consisted of synthesising available evidence on social networks, chronic illness, information, self-management support and alternative strategies (Vassilev et al, 2011); the second involved data collection from a large scale questionnaire study, qualitative interviews and focus groups (Vassilev et al, 2013). The data collected in phase one allowed for development of new interventions as part of...
phase two and then phase three will evaluate the studies involved (Rogers et al, 2011). The current study has been conducted as part of phase one, but in separate interviews conducted by the author of this study.

For phase one of the CLAHRC study, 300 participants were recruited from GP practices in Greater Manchester and the surrounding area. Using the GP lists of people with long term conditions from each of the participating practices, a random sample was taken using the computer programme R. Each selected person was contacted by the surgery and asked to participate by post; those who consented were contacted by phone by a member of the research team and sent a postal questionnaire. The postal questionnaire was developed by members of the CLAHRC team prior to the beginning of this study. Participants were asked to complete the questionnaire prior to the interview, a researcher would attend their home and complete a structured interview. The interview comprised of an in-depth examination of their social network and social status as well as health status. Social networks were examined using a concentric circles system first developed by (Pescodolio, 2006).

This study took place as part of phase one of the CLAHRC study but after the data collection had finished. The aim was to provide a greater depth of qualitative data which allows for the examination of the barriers faced by those specifically with type II diabetes.

5.2.2 Sample

5.2.2.1 Sample size

One of the notable differences between qualitative and quantitative studies is that quantitative studies have much smaller samples; this is because of the different aims of quantitative and qualitative studies. Quantitative studies require large sample sizes to achieve adequate statistical power to support the generalizability of the study findings (Bland, 2000). On the other hand, qualitative studies seek to describe and find patterns and difference in the experiences of people, but not to generalise out to the population. This means that determining a sample for a qualitative study is not as prescriptive as a statistical sample size calculation: It is
difficult to determine an exact sample size before undertaking data collection, data were collected until saturation was achieved (Glaser, 1978)

The only inclusion criterion was the presence of a diagnosis of type II diabetes in a patient’s medical record. Age concerns did not enter, as all participants were aged over 18 in the wider CLAHRC study from which my sample was recruited. Diagnosis of diabetes was essential, as formal diagnosis not only ensures the presence of the condition but also that participants will have had some self-management information from health care professionals.

5.2.2.2 Theoretical Sampling Strategy

To address the primary aim of the study a diverse range of participants was needed to collect differing experiences of the self-management of diabetes. To achieve this, the sampling strategy employed the maximum variation strategy suggested by Patten (1990; 2002), which is a sample selected to offer a range of experience about the phenomena in question. This strategy is especially useful in qualitative studies, which often have small samples because of the large amount of data produced by each participant. Employing a purposive sampling strategy helps to ensure the maximum variation within a small sample (Ritchie et al, 2003). Any common patterns can be considered to be of particular interest.

5.2.2.3 How Maximum Variation was Achieved

Four criteria for sampling were chosen based on a review of the existing literature in Chapter 3 examining barriers to self-management in type II diabetes. This literature identifies several factors regularly linked with lower uptake of self-management practices, these are:

- self-efficacy;
- emotional wellbeing;
- health literacy and
- illness perceptions.

The wider theoretical background of this study is to examine whether or not the
NPT (May and Finch, 2009) can be used to explain how and if people embed self-management practices into their daily routine. So people with high and low normalisation scores were also recruited. The aim of the sampling strategy is to create a sample diverse enough adequately to examine the interactions between individual differences highlighted in the literature and the role of the social network.

No question on health literacy was included in the CLAHRC questionnaire and so could not be included in the sampling strategy, but questions about understanding were addressed in the interviews.

The sample was derived from four criteria. These four criteria were: illness perceptions, self-efficacy, emotional wellbeing and how well the participant feels they have embedded self-management of diabetes into their everyday life.

Illness perceptions and self-efficacy was measured using the validated scales IPQ-R (Broadbent et al, 2006) and HEIQ (Osbourne et al, 2007) respectively. HEIQ was not designed as a measure of self-efficacy but was used as a proxy in absence of a formal measure. The questions designed to look at the participant's emotional wellbeing and how well embedded self-management practices have become have not been validated.

To select those for the sample, firstly the patients with type II diabetes were identified in the (CLAHRC) data set. Other participants were filtered out using SPSS. This left a dataset comprising all the participants from the wider CLARHC study who had type II diabetes. From this list each of the scales were treated separately and participants with the highest and lowest scores were selected. Those with the most extreme scores on each scale were contacted and asked to participate in the study. This continued through the first two phases of data collection.
5.2.2.4 Revision of Sampling Strategy

During the second phase of interviews it was noted that the sampling strategy was not providing a diverse sample or data (see table 5.3 for phases of data collection). Certain types of people were not represented in the sample, particularly women and those who are isolated or from lower socioeconomic statuses. In order to rectify this homogeneity, a list was generated of all the types of people who were represented in the sample, categorised as largely middle class or working class retired couples. A new sampling strategy was developed to target working people, those who had a small social network, were from lower socioeconomic groups and women. The changes to the sampling strategy resulted in a more demographically diverse population which, in turn, lead to more diverse data. The interview schedule can be found in appendix i

5.2.3 Data Collection

Table 5.3: Phases of data collection

<table>
<thead>
<tr>
<th>phases</th>
<th>date</th>
<th>number of participants included</th>
<th>number removed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pilot</td>
<td>July 2011 – August 2011</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Phase one</td>
<td>October 2011 - November 2012</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Phase two</td>
<td>January 2012 – March 2012</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Phase three</td>
<td>June 2012 – July 2012</td>
<td>8</td>
<td></td>
</tr>
</tbody>
</table>

5.2.3.1 Recruitment

Participants meeting the selection criteria were contacted by the author by telephone and asked to join the study. Uptake into the study was very high, with few people declining to participate. This is detailed in Table 5.5. Men represented more of the CLAHRC sample than women; this is reflected in the difficulty in recruiting women to the present study. The CLAHRC study had focussed
recruitment largely on areas which were socially disadvantaged in an attempt to saturate the sample, this allowed for greater access to a population which was socially disadvantaged for this study. However, when the original sampling strategy was used largely middle and working class people were involved as participants. One of the major reasons for revising the sampling strategy was to target socially disadvantaged people specifically. This was done by contacting people who had been noted as “deprived” following the initial interview by the CLAHRC interviewer. It was more difficult to contact these people because phone numbers had often been changed since the original recruitment into the CLAHRC study or phones were simply not answered. This problem was effectively overcome by attempting to contact all those marked as “deprived” in the database. Had the emphasis in the revised sampling strategy not been placed on recruiting people from lower socioeconomic statuses it is unlikely they would have been adequately represented in the sample?

Table 5.4 Numbers recruited

<table>
<thead>
<tr>
<th>Number of people contacted</th>
<th>46</th>
</tr>
</thead>
<tbody>
<tr>
<td>Declined due to time constraints</td>
<td>7</td>
</tr>
<tr>
<td>Declined due to ill health</td>
<td>4</td>
</tr>
<tr>
<td>Denied having diabetes</td>
<td>1</td>
</tr>
<tr>
<td>No reason given</td>
<td>2</td>
</tr>
<tr>
<td>Recruited</td>
<td>29</td>
</tr>
<tr>
<td>Removed from study for not having diabetes</td>
<td>3</td>
</tr>
<tr>
<td>Total number included in study</td>
<td>26</td>
</tr>
</tbody>
</table>

5.2.3.2 Development of Interview schedule

The interview schedule was subjected to several revisions over the data collection period, the biggest changes were made after phase one (see Table 5.3). Significant changes were made at each interview phase and minor revisions during phases (see appendix i for final interview schedule). The initial interview questions were developed from two sources: the first was the findings of the
literature review conducted prior to beginning the empirical study. The second source was the normalisation process theory using primarily May and Finch (2009), May et al (2007) and the questions available on the Normalisation Tool Kit available free online (http://www.normalizationprocess.org/npt-toolkit.aspx).

The interview questions were piloted embedded in the CLAHRC structured interview and delivered during interviews conducted by the thesis author for the CLAHRC study. Following the pilot interviews, more questions were added to provide greater depth for the first phase of full interviews for this study (table 5.3). Following phase one, the interview schedule was entirely overhauled in an attempt to collapse several questions into one single question with a much broader aim. The schedule questions also changed during and between phases to reflect emerging themes in line with the constant comparison method outlined below which was broadly adopted for identifying themes outlined.

Throughout the interviews, the schedule was only used as a guide. Each question was covered in each interview, but in most interviews other lines of enquiry were followed depending on the information coming out of the interviews. This allowed for the development of stories unique to the participant being interviewed and also meant the emerging data were not constrained by the previous work which was used to develop the schedule. Specific emphasis was put on social support and social barriers in line with the research questions.

The data from this phase was lacking in richness, so after this phase the interview schedule was changed completely. To construct the new interview schedule, themes that were highlighted as important by the original literature review as well at the normalisation process theory tool kit remained in the schedule, with the addition of themes from the first phase of interviews. The questions were grouped by theme and then an overarching question was generated to address each theme. This resulted in much more fluid interviews, which were more participant directed and produced richer data. The interview schedule remained in this format with only minor revisions for the remainder of data collection and prompts were used to probe at themes which arose in interviews.
5.2.4 Interviews

5.2.4.1 Pilot Interviews

The pilot phase took place between July and August in 2011. All interviews at each stage of this study were conducted by the author. The first interview questions were piloted as part of the data collection for the larger CLAHRC study. These questions were embedded in the structured interview. This pilot contributed to the study by presenting an opportunity for interview and analysis experience and to assess how participants responded interview questions. The structured interview was a fairly lengthy process involving mapping social networks and rating individual members on various scales which could take an hour or more. The questions for this study followed the CLARHC structured interviews and after this participants were often tired or bored and it became clear that the interviews must be stand alone to achieve the richness of data required.

5.2.4.2 Phase 1 interviews

This phase took place during October and November in 2011. The first phase of independent interviews drew participants from the same sample who had undertaken the CLAHRC interview but the interview for this study was conducted at a different time, usually over a year after the original interview. There were six interviews during this phase. Two participants were removed because the participant did not have diabetes. Before attending each interview the interviewer did not review the participant’s first interview or questionnaire data to avoid forming opinions of the participant prior to the interview for this study.

These interviews drew on the first interview schedule and produced many short answers to questions; lack of experience on the part of the author meant that a lot of more emotive or difficult issues were not adequately probed, leaving gaps in the data. Another problem with the interviewing style was the interviewer sticking rigidly to the interview questions and failing to address emerging themes. Despite this, usable data were produced and interesting themes emerged from the
data. These themes were incorporated into the interview schedule for the following phases.

5.2.4.3 Phase II Interviews

Phase II of the interviews happened after a period of reflection of approximately six weeks between late January and March in 2012. There were ten interviews in phase II; all interviews were included for analysis.

Experience from the first phase of interviews and the pilot interviews was successfully utilized by the author along with the improved interview schedule to produce data with greater depth. The interview was more participant led, due to the collapsing of several questions into more open ended questions. Although this did mean that, at times, participants went off at a tangent and more of the data were not wholly relevant. However, on balance, the longer interviews that occurred in phase II compared to phase I did produce richer data.

5.2.4.4 Phase III Interviews

The final phase of interviews happened after another period of reflection of approximately a month, satisfied with the improved interview schedule and the data being produced, but finding that the stories were very similar it was decided to try a new recruitment strategy targeting certain demographics of people to ensure variety both in the sample and in the data. Eight participants were interviewed.

Due to a combination of growing confidence of the interviewer and coaching from supervisors, these interviews were of much higher quality than the earlier phases of interview. Leaving longer pauses after participants responded to questions with their initial statements resulted in more detailed answers being given, and the flow of conversation improved. The more natural feel of the interviews made the interviewer and participant more comfortable. In turn, as the interviewer was less nervous she was able to concentrate more fully on what the participant was saying and think more quickly with prompts and probes, rather than moving on to the next topic before the last was exhausted. As time went on, the interviewer stuck less rigidly to the script, this resulted in the interviews lasting an average of 20 minutes longer, taking them to approximately
60 minutes. More experience would have improved the author’s ability to tackle more sensitive topics and this continued to be a weakness in the data. For example, there were few attempts to challenge participant statements.

5.2.5 Transcription

The first 15 interviews were transcribed by the author, this allowed for full immersion in the data throughout the data collection phase of the study as part of familiarization (Ritchie and Spencer, 1994). Being immersed in the data from the beginning of the study allowed for the identification of themes early in the study which could then be investigated in greater detail as data collection continued, in line with the constant comparison method (Silverman, 2000b). Another benefit was that the author could identify mistakes and faults in the interview technique; this was very helpful in improving interview technique over the course of data collection. For example, a major problem with early interviews is unnatural jumps from one topic to the next question on the schedule; this was clearly jarring for the participant and resulted in a more formal, less open discussion. As a result, the data lacked depth. While transcribing interviews, missed lines of enquiry were clearly identifiable, resulting in increased awareness during subsequent interviews. For instance, in the first interview the participant received a lot of social support from a male friend; this is an unusual occurrence in the data and it is detrimental to the study that this relationship was not more fully explored. However, in later interviews, when friends were mentioned the experience of transcribing the interview where this was missed had sensitised the author to the importance of following up this theme.

The remaining 11 interviews were transcribed by a contractor in order to best focus the resources of the author on analysis. To compensate for not conducting transcription personally, the author read through the interview transcripts while listening to the interview audio so that nuance of exchanges was not lost in analysis, mistakes were also corrected before analysis.

In total 29 interviews were conducted, 26 of which were included in this study. The three participants who were excluded were excluded because during the interview the participants denied having diabetes.
5.2.6 Analysis

To analyse the data produced by the interviews from all the phases of data collection, a combination of framework analysis and constant comparison methods were employed, using a framework developed from the NPT (May and Finch, 2009; Blakemen et al, 2011, Gallacher et al, 2011), the definitions of this can be found in appendix ii. The analysis strategy went through a series of iterations before framework analysis was found to be the most appropriate method to address the research questions in the given timeframe. What follows is a description of the analysis process and discussion of decisions taken throughout.

5.2.6.1 Trailing Analysis and Gaining Experience

Analysis began following the first interview. This was to develop qualitative analytical skills and to identify themes to explore in later interviews. Transcripts were coded and recoded with developing knowledge and through discussion with supervisors. After each interview, the interview was transcribed and coded immediately by the author. Comparison was drawn between each interview as they were coded, in line with the constant comparison method (Boeije, 2002; Silverman, 2006) outlined below. While these codes were not all used in the eventual analysis, the process was useful and enlightening for several reasons. The first, and possibly most important in terms of the study, was the codes revealed and emphasised the researcher bias towards individual differences to the detriment of identifying social processes. An example of this bias was themes focusing describing how participants felt about practices, rather than what they and those around them were doing to make the practices come about. These social processes are central to the aim of the study, therefore a different analysis method needed to be employed to sensitise the researcher to social processes affecting self-management. Employing a framework approach allowed for the assessment of the NPT for use in this context by fitting the data into the framework where appropriate and identifying those themes which fell outside the data.
5.2.6.2 Constant comparison

Analysis began from the very first pilot interviews; the constant comparison (Boeije, 2002; Strauss and Corbin, 1994; Ritchie and Lewis, 2003) method was adopted from the beginning with inductive coding conducted thematically. The use of constant comparison occurred naturally to build the analysis interview by interview, using a method adapted from Boeije (1999; 2002). Boeije outlined the method of constant comparison used in a study of couples where one person was affected by multiple sclerosis. The five stages of constant comparison are described in Boeije 2002:

- Comparison within a single interview
- Comparison between interviews within the same group
- Comparison of interviews from different groups
- Comparison in pairs at the level of the couple
- Comparing couples

In the present study participants were interviewed as individuals at the centre of a social network; except in rare cases where partners were involved, the final two stages were not relevant to the process. This comparison occurred during the entire data collection and analysis process, albeit with a framework in place for the final analysis.

The benefits of adopting this method were numerous compared with analysing the data once data collection had finished. Conducting inductive analysis from so early in the process helped to identify weaknesses in the data, along with avenues for further exploration in subsequent interviews. This also helped to identify the bias towards individual differences in the analysis which contributed ultimately to choosing to apply a more socially orientated framework to the data. Another benefit was that the method allowed for practise at coding, which was invaluable when conducting the final analysis.
5.2.6.3 Framework analysis

Framework analysis was designed specifically for policy and applied qualitative research (Richie and Lewis, 2003; Ritchie and Spencer, 1994; Gale, 2011; Ward, 2013). The aim of framework analysis is more directed than traditional analysis methods such as grounded theory (Glaser and Strauss, 1967). While the data are still grounded in the lived experiences of those from whom the data were collected, framework analysis allows for aims developed at the outset of the study. The method followed the five stages of framework analysis as follows:

- Familiarization: In accordance with the five key stages of framework analysis the first stage of the analysis process was immersion in the data: listening to interview recordings, reviewing field notes and reading over transcripts. As part of the familiarisation process, transcripts were annotated and a reflective diary was kept. This stage started as soon as the interview stage of the study commenced and continued throughout data collection, informing subsequent interviews as stated above.

- The second stage was developing the normalisation process theory framework. Three papers were used to create the first draft of the framework for this study. The first, May and Finch’s original 2009 paper, was used to understand fully the core concepts of the normalisation process theory. Then the framework employed by Blakeman and colleagues (2012), which operationalized the normalisation process theory, was amended to apply the theory to individual rather than to group concerns, as in Gallacher and colleagues (2011). On application, the theory was successful in sensitising the analysis to social concepts and provided data to address the question of the usefulness of the normalisation process theory in studies such as this one. However, following testing on two transcripts, the first draft of the framework needed development to avoid loss of detail in the data. Work commenced on analysing five more interview transcripts to create more sub themes within the framework concepts to better describe the data.

- Indexing: Atlas.ti was used to code each interview transcript line by line using the NPT framework developed in stage two. During this phase, a
reflexive diary was kept to keep track of coding decisions and maintain transparency. This was done until data reached saturation and no more themes were emerging.

- Charting: These codes were used to populate the NPT framework. Firstly this was done by case and then followed by theme by theme analysis. Special attention was paid to codes which did not fit into the NPT framework and those codes were recorded and organised into themes in a separate chart.

- Mapping and interpretation: description of findings, developing typologies, explanations, concepts and associations.

5.3 Conclusions

Designing and conducting this study has been a learning process and as a result the study design went through several changes throughout the process in order to better address the research questions. An interview study employing framework analysis was the best way to address both the research questions within the contextual limitations of the MPhil. The results of the analysis can be found in Chapter 6.
6 Results

6.1 Introduction

This chapter will address the primary aim of this thesis which is to identify barriers to self-management in type II diabetes. The chapter is organised by NPT component, then sub-divided by each NPT sub-component, themes are then organised into these sub-components. Many themes cross over more than one NPT sub-component because of the complex nature of the practices that participants were attempting to enact.

The chapter considers the following issues:

- coherence which looks at how people understand and place meaning on diabetes and the associated conditions;
- cognitive participation, which includes the themes associated with preparation;
- collective action, where participants describe how they enact practices and overcome barriers to implementation;
- reflexive monitoring, which looks at how people appraise these actions; how people talk about normalisation;
- Themes which fall outside the NPT.

The majority of the work participants describe falls into the categories of coherence and collective action. It is predicted by the NPT that high coherence on behalf of the participant and their network is associated with enacting practices and overcoming barriers. There are examples of work at each of the stages of the NPT. Few themes fall outside the NPT, although this is in part because of the loose definitions of NPT components used to categorise themes.

6.2 Participants

Thirty participants were interviewed, of those 4 were removed and twenty-six were included. Table 6.1 describes the demographics of people included in this study.
Table 6.1 Participant demographic

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6.3 Coherence

Much of the work that participants discussed was focussed on developing an understanding of and beliefs about diabetes and practices associated with diabetes management, either alone or through group process. Along with formal rules regarding diet, exercise and medication regimes, participants talked about more abstract concepts such as healthy eating. Much of this work can be coded under more than one of the codes developed using the NPT. For this reason the same work comes up under several concepts.

6.3.1 Communal specification

Despite the insistence of many participants that they manage their condition alone, beginning with communal specification makes sense as most participants first come to find out they have diabetes in their GP’s surgery. In this study, the majority of participants discovered they had diabetes as a result of routine screening rather than having presented with symptoms. At the time of diagnosis many of the participants were giving a great deal of information to process and they describe conversations about lifestyle changes with their doctor. Others report that their doctor diagnosed them and prescribed drugs but did not encourage them to change anything else about their lives.

“D’you know they didn’t even give me a diet sheet.”

(P15, male)
Participants describe doctors and other healthcare professionals taking varying degrees of interest in self-management. This could be due to the length of time since diagnosis as some participants were diagnosed as early as the late 1980s and self-management support has become a priority in the last decade. Whether GPs, nurses, or other healthcare professionals emphasised lifestyle change or not does not seem to be strongly linked to the attitudes of participants towards self-management practices or to uptake of the practices.

Families were largely supportive and sought information on behalf of the participant. Participants report that families understood about diabetes and associated self-management practices. This understanding appears to facilitate collective action. However, one participant experienced an extreme reaction from his wife (see individual specification for further information), which ultimately contributed to a divorce. It was unclear in this case if the participant’s wife attempted to support the participant before leaving.

“The wife didn't obviously. She actually said she was scared of waking up one day and finding me dead. Um...Bit strange in a way because obviously one day that could happen.”

(P5, male)

Many participants reported that their families sought out information related to the condition and to self-management practices, particularly dietary changes. There were two major themes, the first was children and other younger family members seeking information through the Internet and the second was partners learning new cooking techniques

“No. I was reading a book I got from the library that said steaming was less greasy and everything... The food tastes better for it”

(Wife of P21, male)

“But they (the children) do understand the seriousness of the diabetes. They’ve all got computers now, they can look it up”

(P11, female)
This work was largely hidden work which needed direct question to elicit the information, particularly in the case of cooking where the information often came as a result of having the participant’s partner in the room.

This participant explained how she didn’t think that people did understand diabetes, this was something which could influence collective action in social situations

“No, they just think they don’t understand all this exercise and things you should do they just think it’s a case of not eating chocolate and cakes and biscuits and if you don’t eat that you’re alright. They don’t understand especially on insulin how you don’t miss a meal. They don’t understand anything like that not easy to understand that part”

(P8, female)

Where participants reported having friends with diabetes, many rarely discussed the condition, there was a sense among some participants that talking about illness was not appropriate as demonstrated in the quote below

“No, not really it’s not something that comes up, you don’t talk about health issues. I go out on a Tuesday night, I go out with neighbours and they drink and all sorts of things get discussed. When they told me I had diabetes I didn’t know at the time that he had diabetes, if somebody’s got a leg missing you see, if somebody’s got diabetes you don’t know by looking at them.”

(P13, male)

Others who did discuss their illness most would not go into great detail, trade advice or lean on friends for emotional support. The quote below is typical of the types of conversations participants reported having with friends about diabetes

“Well if each of us knows we’ve gone for a test we say what kind of thing have you got or problems, this sort of thing and that’s usually the end of it. We do tend to know what each of us is taking medicine because it’s usually the same thing.”

(P24, male)
A small number of participants did learn from their social network, for example in the following quote where the participant learns how to manage hypoglycaemia when outdoors

“No, I know because when my cousins Pat said I've had dextrose tablets and I've had the gel it doesn't work, she said I always have a Mars Bar in my bag, I said you're joking and she said no, one of those snack sized ones not the full sized ones”

(P1, female)

Healthcare professionals were not interviewed for this study but there is evidence of a lack of agreement between the medical understanding of diabetes and the understanding that some participants came to. For example the following quote demonstrates the belief that many participants had that they could progress to type I diabetes, seen as a more serious condition. This was conflated with the stages of cancer

“They put me on insulin, does that mean I’m a type one diabetic? She said you’ll never be a type one diabetic in your position, so that was good that. That was a really nice result. You relax a bit then. If she’d have said I was a type one I might have had a different opinion, I might have been a bit frightened into doing things”

(P26, male)

Some participants did not want information from outside sources and felt like they had all the knowledge they needed to manage their condition without adding to it. This theme was present with participants who expressed rebelliousness (see individual specification) but was not exclusively linked to that theme.

“In myself, I manage it myself”

(P25, male)

“I know all the information, I’m 60 love, I know all the information I need to know on food”

(P11, female)
In summary, for most participants, close family put some effort into understanding diabetes and associated practices. This could facilitate both higher coherence in the participant and engagement in collective action. Where there is lack of communication and shared understanding between healthcare professionals, this affects individual specification leading to lower coherence. Some participants do not want to learn about their condition or lifestyle changes which is another barrier to developing high coherence.

6.3.1 Individual Specification

Participants dealt with a lot of work relating to developing their own ideas about what diabetes is, what having the condition means, and placing meaning on practices associated with diabetes management. This work came under the umbrella of individual specification, in part because of the reoccurring theme of self-reliance reported by most participants. Much of this work was the hidden work of processing information and developing understanding more than overtly seeking information. Participants did not report putting a lot of work into managing their condition. “You just get on with it” was a common theme throughout the majority of the interviews. This phrase served a variety of functions in the narrative of the interviews, but it was mostly used to deflect questions about the emotional burden of having and managing diabetes.

“No, I just get on with it, love”

(P11, female)

The theme “you get on with it” was also used when talking about the process of taking up a practice that had become normalised. These were generally described as small changes the participant had not struggled to make.

“You fight it, you get on.”

(P25, male)

Understanding of what diabetes is and how it is developed differed a great deal across the sample, from highly medical interpretations, through a range of common beliefs, to very personal interpretations of the condition. The following quotes demonstrate this range:
Why? I don’t know really. If it’s hereditary, I’m not sure, that’s the only thing I can think of. (P10, male)

“I suppose I’m a bit um puzzled why I’ve got it because I’ve never been particularly over… I’m probably over weight for what I should weigh for my height and size but I’ve always been fairly athletic. I play lots of sport I play golf, I play squash once a week so I was a bit surprised that I got it”

(P24, male)

“I said I eat sweets. He [GP] said ah that’s what’s caused it”

(P4, male)

“the reason why I was sent there was sent there was because I had too many white cells in my blood and that is one of the traces of being a diabetic because it’s disease and the white blood cells are fighting this disease and I’d got more than too many and um the doctor said to me that we have to keep a check on it because it could be borderline leukaemia”

(P11, female)

There certainly was not consensus on the causes of diabetes, although most commonly people cited genetics as the reason they developed diabetes. Another response was those who simply had not considered how they had come to develop the condition.

“I don’t know why, I don’t know why at all. I’ve been told I’ve got it, but how I got it… I can’t do much about it, it’s there”

(P13, male)

How the conditions developed was, overall, unimportant to people and they were more focussed on what diabetes means now that they are diagnosed.

Many participants did not consider diabetes to be a serious or life threatening condition. This was a theme that would present throughout and across interviews. This minimisation could be due to a variety of reasons and serve a variety of functions, sometimes it is difficult to know whether the participants are aware of implications of diabetes to begin with or are in denial about possible outcomes.
At times the context of the interview allows for a better assessment of the function of denial, the follow quotes demonstrate that developing an understanding of diabetes, which perhaps minimises potential harm from the condition, comforts the individual and thus can be considered emotional work

“Now cancer I am scared of. I don’t have that.”

(P4, Male)

Realistically how many people die from diabetes? Not many really, you get ill, but not many people die from it... You never hear of it as a factor, you hear a lot of people getting diagnosed because of obesity and that, but you never hear of people dying. I've got a friend who's got melanoma, a couple of mates who are diabetic all reports you hear about are worst case scenario you lose a limb which is bad enough. But you never hear of someone passing away because they're diabetic.

(P20, male)

I heard about amputations and stuff like that but you don’t see many about, so it’s not as threatening as heart attacks are. Most people don’t survive them, so I was lucky I survived, getting diabetes on top of that isn’t that big a deal compared.

(P13, male)

A second function of denial occurs during interviews in which themes of rebelliousness, doctors as killjoys, and not wanting to change run through the interview. Participants are explicit that they believe that the doctor wants to scare them into behaving in certain ways and they do not believe the scare stories. These two functions are not exclusive and often overlap in the narrative of the interview.

Conversely, themes of acceptance and fear also occur during some interviews. Acceptance was associated with a desire to perform self-management practices. No participant acknowledged the risk of complications without either describing changes made, or expressing a desire to change during the interview.

Only one person expressed fear about the condition and possible complications, despite his comorbid heart condition which had caused two heart attacks he
repeatedly stated his fear regarding diabetes in particular. This fear was developed both individually and through discourse (please see communal specification) but he expressed his resignation to deterioration and death throughout the interview. Despite this he was one of the youngest and most active participants in the study, albeit the only participant who reported pain. He was active in his job and had made significant changes to his diet. Throughout he is critical of his own disease management practices. This is exemplified in his attitude to his current partner.

“She's come into my life to look after me, she's gaining this home, especially now it's paid for. She becomes a shareholder because she looks after me, especially as obviously I will deteriorate over the years and she will be my carer for all intents and purposes. I've managed to pay for the house, so she's me partner. I know technically speaking she's entitled to half of it straight away but morally speaking she's earning it by looking after me”

(P5, male)

His understanding was that having diabetes was very grave indeed. He was the only person who expressed this view, with most participants ranging from those who view the condition as non-life threatening to those who believe that unmanaged diabetes can be life threatening. The participant quoted above is the only participant who view his condition as an inevitable decline until death.

Many participants did say that they were unconcerned about diabetes because they were old, even relatively young participants in their early 60s.

“I've reached 62, there's a lot of people less well-off health wise who are younger than me. I've had a good run anyway”

(P13, male)

In developing an understanding of what self-management and associated practices mean people didn’t talk about “self-management” as an overarching concept during the interviews, but they do talk about the lifestyle changes their doctor wants them to make, how they feeling about making those changes, how they tried to and what they have done. This section focuses on themes relating to
how the participants learn about lifestyle changes and attitudes and beliefs about those changes.

Participants largely left medication to the healthcare professionals, participants established that they either understood their medicine or that they didn’t need to. Medication adherence was strong theme throughout interviews.

“Well, it’s not a burden so much. If you think of the consequences if you don’t take them. I take 7 tablets in the morning and 4 in the evening, two of which are metformin. While you’re taking 1 you might as well take 7. I take 2 with food in the morning and at night with food, I always eat first, It doesn’t bother me at all, I keep all my tablets ready making sure I’ve got them. I just take them because you don’t know the consequences of not taking them”

(P13, male)

The majority of the focus that most participants had was on their diet, this can be seen throughout the results and particularly here, where processing new information and recommendations clashes with a lifetime of perceptions and preferences, even with the sense of self. The dialogue can be divided into three main themes: developing an understanding of what is healthy eating, what is moderation, and the perceptions of healthy diet.

Developing an understanding of healthy eating is often done through discourse with healthcare professionals, family and friends. Once again, a lot of the work happens over several of the concepts of the NPT. However, some of the work is done alone, people report seeking information about diabetes, using the internet or books, learning new recipes and cooking techniques. The results were highly individualised.

“I’ve got recipes where I can make Christmas cake without sugar and I can always make pies and things so. And you find places, sugar free biscuits and... so you just... no he doesn’t really [eat sugar]”

(Wife of P6, male)

Most participants in this study got their information regarding managing diabetes through healthcare professionals and Diabetes UK, although subscription costs
for Diabetes UK were prohibitive for some participants, as demonstrated in the following quote from a long term unemployed participant.

“Well…I joined Diabetes UK but I can’t afford the subscription”

(P2, male)

In contrast this quote from an affluent and well educated participant demonstrates the greater access to information that her circumstances allow her

“If I don’t I find it. By nature I’m a researcher, I started at the technical library in Manchester so I will go and look for where I can find what I want, and if I can’t I’ll ask someone”

(P14, female)

A theme that ran strongly through a minority of interviews was that of rebelliousness, that is to say in the few interviews where this theme was present, it dominated the interview. The theme of rebelliousness was present exclusively in interviews with men. Related to rebelliousness was the sense of self being at odds with the dietary changes associated with diabetes management. This theme is included in individual specification because of the rebelliousness is expressed as both thought processes and acts of rebellion (see collective action). Rebelliousness is also expressed in how the participant interacts with healthcare professionals (see legitimation) and other network members, but during interviews the participants were clear that their rebelliousness stems from their sense of self, it can also be argued that because of this rebelliousness and sense of self fall outside the NPT framework. Where rebelliousness was present participants did not engage with or carry out self-management practices. Healthy diet was perceived as bland, boring and monotonous and as a result very undesirable. Where in other themes that associate healthy diet as somewhat undesirable participants express guilt or regret, those who are rebellious are defiant and therefore do not feel guilty or regret not undertaking the dietary changes associated with self-management. Similarly with exercise there is no expressed desire to undertake more exercise, or dissatisfaction at not exercising. Below is a selection of quotes from participants who demonstrated this theme.
“I told them straight, if they want me to change my diet and stop drinking, I said ‘you can forget all about it. I said I will do what I want’”

(P25, male)

On being asked if he made any lifestyle changes on his diagnosis with diabetes:

“No not really. What are you looking at [directed at wife]? No not really. I eat pies, potato pie and all that kind of thing”

(P17, male)

“Oh I cut out sugar, I’m not a good meal man. I don’t have carrots and all this lot so I’ve got to eat something so I still have me Holland’s pies which I shouldn’t, but I’ve got to eat something.”

(P26, male)

The perception of healthy food as boring was largely linked to rebelliousness but did appear in other interviews where there is the desire to enact practices but there is a struggle to embed and normalise the dietary changes. This is the process of de-normalising existing practices (eating habits) before new practices can become normalised, rather than enacted. This participant lost three stone before regaining two of those, in part because while he managed to enact the dietary changes, he had not managed to normalise them.

“We eat a lot of chicken, but that becomes bland, chicken on its own just is this it? You add something to it.”

(P16, male)

However, even in interviews where the theme was the most prominent, participants reported compliance with medication regimes (see relational integration).

People develop a highly individual understanding of what diabetes is and the practices associated with diabetes management. They place meaning on self-management practices related to lifestyle change based on this understanding. Major barriers including rebelliousness and lack of access to resources to learn about diabetes.
6.3.3 Differentiation

Throughout the interviews, diet was consistently the aspect of self-management which concerned the participants the most, differentiation is a component where this is very clear why: exercise is simply too different from pre-diagnosis practices, or at the other extreme not different at all, i.e. differentiation was either too high or too low. The concept of exercise was seen as silly by some, this was often due to co-morbid disorders or age related restrictions (see contextual integration) largely because of the perception of what exercise is. However, walking, which many participants did as part of their normal routine, was not always considered exercise. The following quotes demonstrates how a lot of participants viewed exercise, although this describes how the participant described exercise before and after a weight management course (see contextual integration) the quote establishes the sense in which exercise is seen as other to every day physical work.

“My doctor said my busy days of getting up at 6.15 in the morning, going out to work for 7.15, climbing in and out of minibus with handicapped children was my everyday life, it didn’t mean I was exercising, but when you join weight management they wanted to know what stuff you did, your housework, your dusting, your painting, your hoovering, they take all that in to account. That surprised me because the doctor said that’s your normal day life, that. They just encourage me to go to the gym and get extra exercise.”

(P19, Female)

With regards to diet, differentiation was varied between participants and was associated with the perception that a healthy diet is boring, pre-diagnosis practices, and normalisation. There appeared to be a middle ground for normalisation where new practices were deemed different, but not too different. For the most part, people reported that their diet had always been healthy but that they had made small tweaks to reduce the amount of refined sugar, often phasing out sugar in tea or eating fewer cakes and biscuits. These are described as minor changes despite them involving de-normalising practices already in place and retraining taste buds.
“was very fond of me fizzy drinks and making the switch to the sugar free ones wasn't easy because at the time they tasted horrible compared to what I'd been used to. That's the biggest switch in my life I can point to and more difficult than you'd think. Getting used to the alternatives to sugar was the biggest change”

(P5, male)

“I don’t eat as much sweet stuff as I used to because I have quite a sweet tooth but you know I tend to eat more fruit rather than cake or chocolate which I used to eat more of before I was diagnosed with diabetes two. But apart from that I can’t say it’s affected my life a great deal.”

(P24, male)

A common change amongst the study participants was to reduce the amount of takeaways they had. This was done in relation to how many they had before, so those having many would cut down to one a week, those having a weekly takeaway would cut down to one a month.

“Maybe a Saturday night we get a curry. We stopped doing it, now it’s every month or 6 weeks”

(P16, male)

Those who perceived a healthy diet as boring viewed the salads and boiled chicken they associated with diabetes related dietary changes as very different from their current diet. This difference was often expressed as too different to change, there was no regret associated with this.

“P: I’ve read the information, I’ve had the same [food] all my life
PW: You shouldn’t be having pies. I can’t tell him
P: I like a pie”

(P10, male)

More often than not people did not perceive a healthy diet as significantly different from their pre-diagnosis diet, some described minor alterations which were viewed in a positive light.

“The dietician who came said that you don’t have to be too strict with the diet, you can have treats and things like that occasionally, so I do occasionally.
Otherwise it doesn’t affect my life very much really, because I’m careful with the
diet, you know, with what I eat. I try to eat sensibly, otherwise carry on”

(P23, female)

Overall small, easily identified changes had a greater chance of being normalised,
changes perceived as either very different from pre-diagnosis practices or not
different enough were dismissed by participants.

6.3.4 Internalisation

It was common for participants to have shifted to a healthier diet following
diagnosis with diabetes. However, managing diabetes was not at the forefront of
decision making regarding food for most participants, even where the initial
changes were made in relation to diagnosis. This could arguably be considered
normalisation, but the decision to make healthy choices continues to be work of
sorts. This falls into the translational work described in section 2.2.4. The
participant in taking the meaning derived from individual and communal
specification internalises a list of rules for healthy eating which have mentally
become divorced from diabetes but for which diagnosis of diabetes was a
catalyst. It is the process of translating the combination of beliefs and meaning
the participant has placed on dietary changes and transforming them into more
practical knowledge which becomes part of the life of the participant, but has not
become embodied in a way that some of the practices coded as normalised have.
The quote below shows how healthy eating becomes divorced from diabetes
management, even though this participant made the changes to manage his
disease

“I don't consider my diabetes first, but I tend to choose the more healthier option
because when it comes to food”

(P5, male)

It is difficult to provide a single quote to illustrate this as it is a hidden process
which is reveals itself throughout the interview. In this study, the code related to
translating abstract meaning and beliefs becoming functional rules for eating
which are applied without relation to management, but rather as part of life.
6.4 Cognitive Participation

Participants in this study did not discuss a great deal of work associated with cognitive participation, there was more intellectual and emotional processing carried forward from individual and communal specification, the majority of which centred around legitimation. Other cognitive participation work involved planning for potential difficulties or crises.

6.4.1 Legitimation

Originally the theme of moderation was coded as an individual specification theme but on review it became clear that the term moderation served the function of legitimising consuming foodstuffs that were not considered ideal for people with diabetes. Participants refer to times when their doctor or nurse told them to have what they wanted in moderation. It was a theme that ran throughout many interviews, participants reported that they were told to have everything in moderation. Moderation is an abstract concept and there is some individual specification work in determining what moderation means, but the function in the discourse was primarily legitimation. When prompted the term moderation was also used when talking about achieving balance between enjoyment and managing diabetes (see concepts which fell outside the NPT)

Strongly associated with rebelliousness (see individual specification) was doctors perceived as killjoys. Here the participants painted doctors and their advice as boring, the advice was not legitimised and was dismissed

“[If] he had his way I’d be eating boil in the bag bloody fish three times a day, you know. Mashed potatoes and stuff like that. Well mashed spuds is alright once a week, once a fortnight but I couldn’t eat mashed potatoes seven days a week”

(P4, Male)

In contrast to this, good relationships with healthcare professionals increased legitimation. In the case of the first quote below the participant asserted throughout that his eye surgeon was his primary source of information regarding
his diabetes management. The participant refused a knee operation due to his
dislike of the surgeon who would perform it. This operation would have
improved his mobility and therefore improved both his quality of life and ability
to management his condition through gentle exercise.

“I’m supposed to have a new knee, but I didn’t like the person I met at the MRI
when I went to see about this”

(P25, male)

“No, I didn’t worry about anything, I phone her [retired nurse] now at home,
she’s even left the doctors, but told me she could phone me at home if you’re
worried about anything. Obviously she can’t give me anything, but she can
recommend for me to do something... That’s her gone now, I won’t get one half
as good as her...”

(P26, male)

Increased legitimation of information and practices through legitimation of
healthcare professions did not ensure uptake of self-management practices, but
where there was a lack of legitimation this was a barrier to undertaking practices.

6.4.2 Initiation

Aside from taking their dietary changes into account when shopping, few people
talked about preparing for possible problems. Two of these people decided to
carry around sweet foods in case of low blood sugar as demonstrated in the quote
below. Another participant had planned to carry around sweet foods, having had
effects from low blood sugar in the past but had not yet put this strategy into
place.

“No, sometimes when I go out now I’ve always got some biscuits or something in
me bag and when I go on these day trips might go to Blackpool and we’re going
to have a meal when we get there I always make sure I’ve got a bottle of
Lucozade in me bag and some biscuits and I’ve never had to use them but if I
know I’ve got something there, just in case the meal is going to be a bit late.”

(P8, female)
The following participant with a range of health problems which had left him housebound had installed a button in his home in case of a fall. This wasn’t directly related to diabetes management, but rather management of his multimorbidities

“If anything happens to me, I push the button, if I fall and I can’t get up. They’ve got the keys, I’ve got a set”

(P4, Male)

6.4.3 Enrolment

Another facet of the above participant’s management and planning was having ensured his friend, who helped with his self-management by shopping for him (collective action), was a key holder to his home

“He’s a key holder, so when he comes of Saturday morning I don’t have to press the bell to let him in. He rings the bell first, then lets himself him. He’s got a set of keys”

(P4, Male)

It is possible that cognitive engagement work is hidden and not revealed in this study because all the participants in the study had been living with the condition for some time, approximately from five to twenty years. Much of the planning and enrolment may have happened in the time following diagnosis.

6.5 Collective activation

6.5.1 Contextual integration

This section looks at contextual barriers to implementation of self-management practices that participants identified and efforts, successes and difficulties in overcoming these barriers. Contextual barriers include any barriers relating to resources, environment and social activities. Contextual integration is about embedding practices within the context of the life of the participant. Although barriers were diverse and often individual to the circumstances of each
participant, they do fit into four broad themes: personal, social, environmental and financial.

6.5.1.1 Personal

Many participants had a co-morbid disorder and many of these reported multiple co-morbidities. These disorders were diverse and included asthma, heart disease, back pain, and fibromyalgia along with complications of the condition such as leg ulcers and blindness. These disorders were the most prominent barriers for participants in this study, primarily to exercise; two participants were almost immobile and rarely left the house.

Others were still mobile but their co-morbid disorders acted as a significant barrier to undertaking self-management practices

“I’ve been told by my doctor and the diabetes people that exercise is very important, obviously weight loss helps. Because of my asthma and my back I can’t do exercise”

(P16, male)

“I finished with back problems, then I started swimming properly, because it’s the one exercise you can do that doesn’t affect your back. I used to walk up to the baths in Duckinfield, do 40 lengths, then walk back. That was giving me good exercise, but then heart attack came and that put an end to that, they told me not to swim. You can go in the water and flap around, I just wanted to get in and swim up and down without that there’s no point going. The only exercise is walking.”

(P13, male)

Other participants discussed how they prioritised other conditions which were seemingly more pressing, whether it was due to pain or the fear of other conditions.

Conversely, for some people management of multiple conditions reinforced the importance of self-management and practices overlapped for each condition, this was particularly true of heart disease.
Shock can effect self-management, but this appears to be a time-limited facilitator. In this case Bell’s palsy, encouraged the participant to adhere to self-management practice but over time people did not manage to normalise practices as a result of a shocking event

“I’m supposed to see him in March, I lost about three stone because I had Bell’s palsy a couple of years ago I thought I’d had a stroke and I got in to the regime of eating correctly... That was a scary episode, I thought it was a stroke then they told me it was Bell’s palsy that I’ve never heard of. I started to lose weight, but slowly but surely the bad things start coming back in purely and simply because it’s a pain sometimes to isolate my food as against others who live here.”

(P16, male)

“Er no. (laughs) I did at first, then I had a heart attack in 2000 and I went rehab for that and there was a lot of exercise involved in that. Um... but I don’t, I probably don't do as much as I should, let’s put it that way”

(P2, male)

Where people had painful conditions, managing the pain associated with other conditions was a priority over managing diabetes and predominantly acted as a barrier to exercising. However, in some cases people with heart disease found that the practices overlapped and this reinforced practices, particularly taking exercise.

6.5.1.2 Social

Social barriers describe how the social network acted as a barrier or a facilitator to undertaking self-management practices. This section contained many themes which were diverse and encompassed the role of family, friends, and health care professionals. Prominent themes involved managing social situations, eating foods bought for other family members, family and friends supporting self-management, and positive and negative contributions of health care professionals.

Participants did not often identify social situations, in fact some people seemed affronted that it was suggested that they may be swayed by other people, other
participants did not want to implicate other people as barriers to managing diabetes. Despite this there were several ways that social situations and social obligations which contributed to people struggling to embed self-management practices.

The first was that people who would avoid sweet treats kept them in the house for their grandchildren. Having the temptation so close was too much for some participants who found themselves eating the treats they try to avoid. The desire to please grandchild was more important than keeping tempting foods out of the house.

“It’s a question of getting your mind-set altered, and it’s just so hard. I’ve got 4 kids, 6 grandchildren, you buy them toffees and I’m a picker. If they leave chocolate I’ll eat it, it’s stupid really, but it’s me mind-set I’ve got to sort myself out.”

(P16, male)

“I like baking and I always were baking cakes, mostly for when the grandchildren come and that if they’re there then it’s tempting him.”

(Wife of P9, male)

Other participants had strategies for balancing the desire to have treats in for others without indulging in foods which may negatively affect their disease management

“I said I like the treats in for the lads, but I buy the ones I don’t like so won’t eat them.”

(P19, female)

Many participants offered practical support to family members. Sometimes this support couldn’t always be precisely scheduled, such as in the case of a participant who talked about having to drop what she was doing when her daughter would telephone her for a lift in her car. Most of the times this was not acknowledged as a potential barrier to self-management, although some participants did find the unpredictable nature of family commitments could affect their ability to undertake the practices they needed to. The experience of the
participant here demonstrates how family commitments are prioritised over self-management practices

“I go to the gym twice a week which the weight management have introduced me to the gym to help me go twice a week, it gets difficult sometimes because I have my grandson here and it gets here there and everywhere”

(P19, female)

Elsewhere in the same interview the participant elaborates on why caring for her grandson is a priority over going to the gym

“I think if you’re a caring family you need to not be selfish. I have thought to myself why I have to not do things for myself and do things for someone else”

(P19, female)

With regards to food most participants had formed strategies for managing meals with family and friends. Those that did not were not concerned about socialising with food affecting their management. Some incorporated healthy eating into family meals through increasing vegetable content, others had rules to choose the menu options that were aligned with the diet they were following.

“If we go out for a meal I have two salads and I don’t have a lot of chips and things like that, but otherwise I just have what I have really”

(P23, female)

Families and friends would often consider the diet of the participant or other special requirements as exemplified by the following quotes:

“They [friends and family] accommodate me. They find out what time you need to eat and we eat at that time. Yeah, they all fall in line”

(P6, male)

High blood sugar on occasion wasn’t a concern for participants, particularly if it was following a special or social occasion. To have high blood sugar after such an occasion was seen as part of the balancing act of managing diabetes and enjoying life by most participants
“I keep it more or less stable. I went mad once when it went up to 21 but we were on holiday so…”

(P9, male)

Participants who were taking insulin found strategies for injecting while at social gatherings with food or adjust their medication around their social life. Better medications have made this easier for participants now that the insulin does not need to be taken twenty minutes before food. These quotes demonstrate different strategies for managing insulin and social gatherings:

“You’ve got to leave the table to go to the toilet, you’ve got to put it here so you can’t start going like, that’s the only thing that gets to you, you’ve got to leave the table.”

(P8, female)

“…so when we go out it’s nine and when we come back it’s 12. So I take it three hours later, I haven’t forgotten, but I don’t take it with me to take it to the loo or what have you, I take it when I get home”

(P26, male)

Reducing alcohol intake was an important change for many participants, alcohol was perceived to be one of the worst things they could consume, after refined sugar:

“Well he obviously said watch what you eat and drink I suppose and the main thing is make sure you don’t over drink which is fatal isn’t it”

(P24, male)

All participants who had been heavy drinkers reported reducing their alcohol intake considerably on diagnosis, none of the participants in this study found it difficult to do so. Some of those people report a significantly reduced social life as a result but do not regret their decisions. Those who continue to socialise with alcohol do report increased consumption in social situations but this is not viewed as a problem and was a conscious decision.
"I’ve not had a drink for 18 months, I just stopped. I used to be 12 pints of Guinness and a couple of vodka chasers a night. I just have wine and soda, but then I told that to my dietician, he said you can do without the wine. So it’s just a vicious circle really."

(P16, male)

Partners were very supportive of healthy eating in the home, learning new cooking techniques (see communal specification) and putting them into practice. Many partners changed their diet along with the participant, this was true of those who cooked and those who were not the family cook.

In some cases the behaviour of partners could act as a barrier to self-management, for instance the quote below which shows how the eating habits of the husband negatively impacts the eating habits of the participant

“My husband when he had his heart attack he started doing race nights and used to be in pubs, what’s open when you leave a pub? Takeaways. When do you eat it? Late at night. What’s happened to all you food? You’re gaining weight. They say why do you need to eat, I say I’m hungry, I’ve had me tea 6 o’clock, it’s midnight, I can’t go to sleep hungry, so you buy a takeaway and all that accumulation in me gaining weight”

(P19, female)

Despite the assertion that participants manage their conditions alone, in the majority of interviews there are examples of practical support from people in participants’ social networks which facilitates the participant in overcoming contextual barriers. Wives, in particular, provide a great deal of practical support including arranging appointments associated with diabetes management, cooking, and adopting the same dietary changes as their partner. In this quote, the participant talks about how moving in with his wife changed his lifestyle dramatically. She cooked healthy food from scratch which were much more in line with the diet recommended by health care professionals than his diet as a single man. While this change was not made specifically to improve his disease management, the result was that he was eating a diet that enabled him to control his diabetes better:
“Yeah it’s [blood sugar] pretty consistent... since my wife got me on veg...it happened when we moved in, just changed my lifestyle. When I was single it was takeaways, tinned food, easier. Since getting married it’s proper food”

(P20, male)

Another participant talks about how his wife started cooking more healthy food when he had his heart attack and was diagnosed with diabetes. They eat fewer takeaways and more home cooked food:

“...by making me much healthier food. We do eat out and takeaways occasionally as a treat, but she does a lot of cooking with proper ingredients, not just slapping things together. She looks after me in that respect.”

(P13, male)

Wives also changed their diets along with their partners which, as the quote below demonstrates, is a support to continue to enact the dietary changes associated with diabetes self-management:

“No not really because we’ve both done it I suppose my wife is on various diets and we’ve both cut it out because we both have a fairly sweet tooth so I haven’t found it difficult.”

(P24, male)

“Yeah but not in a bad way. I don't mind it, I think it's perhaps been better, you know healthier for me as well”

(Wife of P6, male)

Many participants who did not drive, particularly the older participants, relied on family to give them lifts to the shops and to healthcare appointments. This participant had to stop driving after a near crash and subsequent diagnosis with Parkinson’s disease. Since then she relied heavily on family to give her lifts

“No, I’ll get one of the kids to drive me. I’ll get them to drive me, I mean Gillian comes in a couple of times a week, 2 or 3 times a week and we’ll go out, we’ll so a shop, or go and have a walk round. Or we’ll go to the Trafford Centre or go to
the Lowry centre in Salford, we’ll do something. Judith my son’s wife works from home so I’ll say to her come across.”

(P22, female)

This was a theme through many interviews and there are many examples of participants relying on family with cars to get to medical appointments, shopping or for social outings. Without this practical support many participants in this study would have struggled to with everyday tasks both associated and not associated with self-management resulting in a distinct decline in quality of life.

Social network members also support participants in enacting, embedding, and adhering to lifestyle changes. This support is often described as “nagging” but the encouragement is viewed favourably by most participants except those who felt rebellious towards the self-management practice. Partners, children and grandchildren all provided this support and encouragement.

“P: Yeah, I don’t think I’m a serious diabetic. It’s only tablets, I don’t have injections or anything like that

PW: It could lead to it

P: Eh?

PW: It could lead to it if you don’t look after yourself

P: I’m taking the tablets

PW: We’ll make an appointment to see the nurse

P: Well she should have said really

PW: Yeah but she’s not is she? You wait for her you could be dead

P: Awkward patient”

(P10, male)

“My wife, whatever I don’t do she tells me, and what I don’t do she shouts, she’s helping me”

(P26, male)
“It does and it doesn’t [annoy me], sometimes I think I’m married to more than one wife. But then I reflect and I think they’re all after my best interests, and that’s good.”

(P16, male)

The majority of the participants had close family who took responsibility for self-management support, both practical and emotional. The few who did not find that friends took on these roles, for example one participant who was housebound due to a combination of leg ulcers and being unable to afford the insurance on his mobility vehicle, had a friend who would come over once a week with shopping for the participant. The participant wrote his own shopping list and because of this did not view the friend shopping as support with self-management, this is an example of the hidden work done by those in social networks that goes unacknowledged by the participant.

“Me friend comes at the weekend and does me shopping and me washing”

(P4, male)

There are also examples throughout interviews of support from neighbours such as in the following quote

“Yes, but because I was diagnosed the other day with Parkinson’s, which is not too bad if you can see. I just told the next door neighbour and he’s been knocking, is there anything I want, can I get you anything, I’m going to the shop there’s no point in both of us going, that’s the sort of person he is. He’s a bachelor, he’s on his own, so. He always comes to us for his Christmas dinner and things like that, he’s a nice guy. He’s about 77/78, but he doesn’t look it. He’s very good.”

(P22, female)

“My next door neighbour was a merchant banker, he chops trees down, mows the grass, he does all sorts of little things for me. My neighbour that way, her husband has MS, but on one occasion I broke my ankle and she was in and out of here every morning, going to get my bread, so there is a support system here.”

(P14, female)
The same participant also reflects on the absence of these relationships. When she was living in London her blood sugar was much higher, she considered her diabetes out of control:

“When I moved to London I had a GP who I didn’t know like I do here. I think there’s confidence in familiar and I didn’t have the support of long term friendships.”

(P14, female)

Dog ownership was a facilitator to exercising, those with dogs felt bound to walk them with the benefit that the participant ended up exercising too.

“I wouldn’t say it’s [encouragement to exercise] so much Debbie, I’d say it’s the dogs, the dogs need their exercise. The dogs come first.”

(P15, male)

The practices, barriers and facilitators associated with self-management have complicated interactions, as stated above co-morbidities can act as a barrier to exercise, but also sometimes as a facilitator where management practices overlap, such as in heart disease. This also had a social aspect because as part of treatment following a heart attack people are giving support to exercise in a formal, healthcare environment which they are expected to attend. This support from the healthcare system and the social expectation attack led to the participants adhering to the exercise schedule. Once the course was finished many of the participants stopped adding exercise to their routine.

The benefits of extra support from the healthcare system are further supported by the experiences of a woman who attended a weight management programme through the local primary care trust. The programme supported people through tailored information, emotional support and encouragement, and by increasing access to resources such as the gym. The participant was very positive about her experience of the weight management programme. On achieving a loss of ten per cent of her body weight she had to leave the programme, without the support offered by the programme she felt abandoned by the system, she still had some support and monitoring but not the intensive emotional and practical support offered by the programme. As a result the participant was exercising less, and
had started to regain some weight although she was aware and planning to maintain the practices she had been enacting during her time on the programme.

“The doctor put me in touch with them, there’s a doctor, a dietician, a psychiatrist and the ladies that weigh you every week. It was supposed to me a 12 month programme. They try to get you to lose 10% of your bodyweight, and when you’ve done that they kick you out, but I’d lost 20% in 18 months... I got kicked off which is why they put me in touch with fresh start because I didn’t think I’d be able to keep the weight off on my own. My weight catches up with me because I get sad when it’s dark I want carbohydrates and stodgy stuff. I enjoyed going to weight management because we all got on well. I wasn’t the oldest or the youngest, it was mixed age and a lot of them were heavier than I was when I started, never mind when I finished... I said at the beginning I don’t want to be losing weight then you abandon me all together because I know I won’t keep it off on my own. I need somebody who’s not family or friends to tell me to pull my socks up and get dieting.”

(P19, female)

The sense of abandonment this participant felt following finishing the weight management course was a theme throughout the interview as was her resultant weight gain.

“When they said I couldn’t go any more to weight management I just said you’re abandoning me. I don’t want that, I want someone to keep an eye on me because I know what will happen, I’ll start putting weight back on and I don’t want to do that.”

(P19, female)

“I felt comfortable in weight management, I didn’t want to go in the first place, because I thought it wouldn’t do any good, but it did and I felt great... I’m panicking now because I know me, if nobody’s tells me I’m slipping, I know I am, but if no one says come on you’re going back to what you’re doing before I’ll put it back on and I’m not getting that support now.”

(P19, female)
Conversely, lack of tailored support stood out for some participants, it appeared to add to the sense that lifestyle change was unmanageable for them. In the following example, the participant was given advice about exercise to manage his condition when due to his co-morbid disorders he was unable to exercise:

“They do, they give me sheets about these clubs that go for walks, and I can’t walk”

(P16, male)

Many participants found accessing healthcare to be very easy, the quote below exemplifies the experience of many participants

“I could ring up today, get an appointment tomorrow. Whatever questions I’ve got they’ll answer or arrange for me to go and see someone, I’ve no problems with that.”

(P13, male)

Access to healthcare was sometimes more difficult for people in built up urban areas, this theme could be considered social or environmental as the environment inhibited access to care. In these areas some participants found that some practice structures meant they had trouble getting appointments in a timely fashion, or they could not see their preferred health care professional. This was not the experience of the majority of participants, but those who did experience problems accessing health care all lived in the less affluent areas of Manchester.

Socialising was not a major barrier to participants enacting practices relating to dietary management, those that wanted to engage with self-management practices found strategies for choosing foods or limiting alcohol intake. Participants with more social support found enacting management practices easier. When social support is withdrawn, it becomes more difficult for participants to continue with specific tasks associated with disease management. Formal support from healthcare professionals is particularly important for participants in this study to fit exercise into their routine, where compliance but not normalisation occurred during times of intensive support from the healthcare system.
6.5.1.3 Environmental

The environment acted as a barrier or a facilitator to enacting self-management practices associated with exercise and diet, this was largely based on whether or not the participant lived in urban areas of more affluent suburbs and semi-rural areas. Working environments also impacted on the ability of people to manage their conditions.

Those who worked found that their working environment hindered their ability to adhere to their dietary changes or to exercise. Two of the participants who worked had jobs driving which meant that they struggled to have healthy meals throughout the day, or to eat at the times they needed to. Both participants found this to be a particular burden and had little support from their employers to manage their condition. In addition to this, one of the participants was an insulin user whose uniform preventing him from injecting at the times he needed to, meaning he had to work his insulin injections around his work schedule.

“I started off on two different types of insulin, one for the evening, one for the morning, sorry, the same one for the morning and the evening and then introducing another one for after the main meal during the day which doesn’t work as my jobs cash in transit so I’m in a van all day, on my own, with body armour, so it’s very difficult to put injections in at some point when you don’t stop all day. Work’s not very sympathetic, so if you were to stop for half an hour to an hour to an hour to have your insulin or something with food or have calm down, they go spare. They don’t tell you that, but you know that, because you wouldn’t get to do your route.”

(P20, male)

“It upset me a little bit because it was a threat to my living being a wagon driver and they wanted to make me inject. But once they realised I was a wagon driver they changed me onto tablets and diet, which I’ve been on ever since. So, I was a bit upset because it would have affected me living at the time”

(P5, male)

The constraints of work were mentioned in relation to attending the weight management course discussed above, the participant made it clear that this course would not be possible for her if she had still be employed because of the times of
the meetings. While this was not a barrier to the working participants in this study it is another example of how inflexible working conditions could impact on the ability to manage should the resource be made available.

“When I first went to weight management there was no way anyone who was working could do the sessions I did, they’re either during the daytime or there’s none. So anyone who was working, unless they were working part time and could fit it in, there’s no way they could go.”

(P19, Female)

Safety was an important environmental factor, those participants who lived in unsafe urban areas were restricted and unable to go for walks. This is in contrast to the participants who were more financially secure who tended to live outside the city in semi-rural areas where the participants perceived themselves as safe. These participants were able to go for long walks as part of their diabetes management, this also contributed to their personal well being.

“No I won’t [go for a walk]...there are lads that hang around on the corner out there [indicates to small grassy area directly outside house]”

(P12, female)

However, when there were pleasant places in the vicinity the urban environment becomes less of a barrier, as demonstrated by this participant living in Levenshulme.

“I got myself some walking boots because it's pretty muddy over High Field. ... but once you've got out it's good and you wouldn't believe it but it's only just down the road High Field and it's a country park and there's all the wildlife and that and I'm interested in that, wildflowers. Um... animals and birds and things... so we have a good time. But then, like you say, and Irene, she'll say to me are you alright, do you want to go any further or sit down and I'll say I'll sit down if what's she called? “

(P1, female)

Those in the most deprived areas, where amenities are low, found getting to the shops more regularly difficult. Many people living in these areas did not drive...
and therefore had to rely on public transport, taxis, or lifts from family to get to the shops. As many of the participants in this study were older people, carrying large amounts of shopping on public transport was not an option. They had to take taxis making the cost of shopping regularly prohibitive. One couple, living in an area where houses were being demolished and amenities were closing down, reported that they were only able to shop once a month because of the price of taking a taxi to the shops and back. A result of this was that they lived off frozen food and had little in the way of fresh food in their diet. Despite this, they did work hard to ensure they ate a healthy and balanced diet, it was just more difficult for them. In contrast, one well off participant when in a position where she was unable to get to the shops due to having two broken ankles had her fresh food delivered to her home by the local butcher and greengrocer.

“I broke my ankles, my daughter and my grandsons moved in, so I Tesco online, did it, the man came, papers delivered, milk delivered, phone the butcher he comes down with it…”

(P14, female)

One participant talked about the increasing prevalence of fast food outlets in his urban area and the associated temptation to eat foods which would adversely affect his condition management. Not only are these foods high in calories but also cheap and quicker than cooking at home. This participant questioned the role of local government in allowing this proliferation of unhealthy food outlets, while at the same time encouraging healthy eating by the local population. He argued the government had a responsibility to support people in making healthy choices by creating an environment where healthy choices are easier to make.

“They seem to think its people overweight, that it’s their own fault, but it’s not. If the powers that be were more aware, and they must have been, they could have done something about it by not allowing these shops to open. If you were to drive down the road you’d pass 30 or 40 places to eat, fried chicken, curry houses, kebabs, McDonalds, KFC, all the way down. Easy access, easy food. On a Friday me wife cooks, she needs time off, so every Friday we go to the chippy, fish and peas and a few chips. One bag between us all. That’s easy. You can’t expect anyone to constantly cook.”
From these interviews the benefits to self-management of living in an affluent area was clear, participants in socially deprived areas felt a burden of organising and conducting self-management practices which was not felt by those living in affluent areas.

6.5.1.4 Financial

The section 6.4.1.3 contains examples of how living in a more or less affluent area can affect self-management for a variety of reasons. This sub-section will cover the financial barriers which are not already covered throughout the rest of the chapter. These barriers largely come under the two themes: smaller food budgets and financial barriers to accessing resources. As exemplified in the following quote, smaller food budgets mean that people have to direct their limited resources to less nutritious, calorie dense foods

“We’re a bit tight we tend to stick to the stodgy stuff because it fills you, so if money’s tight we buy more of that because it fills you for longer, and it’s wrong, but it’s cheap”

(P19, Female)

Others just can’t afford the foods they enjoy which affects their wellbeing:

“That’s gone to once a month, but there’s cost involved. You’ve got to get worse with the Tories, I remember Thatcher.”

(P16, male)

Two female participants talked about attending the weight loss group Slimming World. Both were living on limited budgets and both found that the cost of the programme was prohibitive.

“I went to Slimming World and it was a lot of money. It was alright when I was working.” (P19, Female)

As described in individual specification, the cost of Diabetes UK subscriptions were prohibitive to people on lower budgets.
Lower income affects a range of self-management practices, including shopping, buying foods recommended for self-management, and accessing information, resources and support.

6.5.2 Relational integration

Those people involved in self-management support were either paid professionals or family and friends of the participant. The work of developing these relationships was done either in the past of the relationship is assumed through the professional nature of the relationship or familial responsibility. As a result the work was not often talked about in the interviews. There are a few exceptions which will be addressed in this subsection but this study did uncover much of the potentially hidden work of developing relationships.

Many participants did have favoured healthcare professionals, which contributed to legitimation, aiding their self-management through that process. It is difficult to know from the interviews if these relationships are reciprocated or lead to greater support as the narrative is only known from the side of the patient. There are examples of favourite healthcare professionals giving excellent care such as the following story, and this surgeon remains involved in the care of the participant, but it is unknown if she treats all her patients with equal care

“I just phoned her out of the blue and told her, and she said you get in here right away.”

(P25, male)

Those participants with dogs got exercise through walking the dog, but also found dog walking a social experience. One participant walked his dog with a neighbour at least once a day, while the other dog owner in the study reported that people stopped to talk when he had the dog. Having the dog allowed them to foster social relationships which resulted in them receiving both practical and social support including self-management support.

Participants reported practical support from people in their local community. This was reciprocal and beneficial, particularly to older people. The type of area people lived in appeared to have no effect on whether or not support was offered.
This was coded under both social support and relational integration but included here to show the reciprocal nature of these interactions and support.

“I’d never knock on their door. That’s what they’re like. Years ago that’s what it was like. We all look after each other, we don’t intrude. We stick together.”

(Wife of P21, male)

6.5.3 Interactional workability

All participants were reported high adherence to medication schedules. This was very important to many of the participants and most had developed strategies to prevent them forgetting to take their medication. These included: alarms, keeping medication next to the participant’s usual chair, and organising medication to take to work the night before so it is not forgotten in the morning. Here are some methods people employed to remember their medication

“Tonight when I’m dishing them out, I’ll be dishing them out for the whole weekend because I’m away. Normally I would dish out what I needed for tonight and dish out my morning ones too. I put that in a container that I can put in my pocket quickly. I usually put it in my bumbag there. Just before I go out the door, just in case I don't have time before I go to work”

(P5, male)

“And I have to have my phone telling me because I would forget”

(P11, female)

Arguably these strategies could be coded as reconfiguration, as they are strategies set up to prevent the participant forgetting to take medication based on past experience. Here they are coded as both, because implementing self-management practices is ongoing work. Cross over of codes is inevitable. The quotes have been included here to show how work gets done.

For some people they it gave them a sense of control over the condition to take their medication. One participant knew that if he took his medication he was fighting the condition, if he developed complications he still knew that he had taken action against this.
“I’m very careful to make sure I take them, that way I know I’ve not done anything wrong myself. It would seem silly to have the opportunity to control the diabetes with tablets and not bother.”

(P13, male)

For some people with multi-morbidities they were very used to being on medication regimes and the diabetes medication was fitted in with the other medications they were taking.

“I take 7 tablets in the morning and 4 in the evening, two of which are metformin. While you’re taking 1 you might as well take 7.”

(P13, male)

The majority of participants reported no problems with their medication, when asked directly about problems or side effects participants often expressed surprise that difficulties with prescription medicines was a consideration. One participant found taking pills “a bind” but despite this he adhered to his medication schedule

“I take the metformin two tablets four times a day, no I don’t I take them twice a day and I mean it’s a routine you get up in the morning and take your tablets and you take them when you eat in the evening. The only time there’s risk of not doing that is if I miss a meal and then I usually remember to take them before I go to bed so I’m pretty good on tablet control”

(P24, male)

The following exchange between a participant, who did not change his diet and did not intend to and did not display any negative feelings about this, and his wife demonstrates that medication adherence remains important to participants

“PW: And making the appointments. He’s very stubborn that way aren’t you?
P: Well there’s no use going to the Doctors...

PW: That’s what they’re there for, I think you should have a check-up of that. Because he had to take his thingy every morning or twice a week didn’t you? And he just stopped it cause they’re not interested. You’re still having the tablets aren’t you?
P: Oh yes”

(P10, male)
Participants were also adept at managing insulin. All of the participants who were using had not found the process of finding the correct dosage and the ongoing task of managing injections and dosage according to need to be a burden, they report finding it to be intuitive or “common sense”. Participants change their doses according to their needs. The following quote demonstrates how the participant has normalised his insulin use to counteract the effect of his alcohol consumption. He had stated previously in the interview that he drinks approximately three pints of beer a day (he reduced his intake from eight or nine pints at day).

“I inject enough to compensate for having a [alcoholic] drink and having a meal”

(P25, male)

Exercise was not a priority for most participants. There was little in the way of strategies for embedding exercise, in those who had embedded exercise it coincided with activities they found pleasurable such as dog walking, golf or gardening. For those who did exercise exclusively to manage their health, social support either through the health service or from family was important to ensure disposal of work.

“Well you probably walk more than you did before. Because you know it's good for you so I think you tend do it on a regular basis whereas before you would probably go in the garden or mess about in the garage.”

(Wife of P6, male)

Diet was at the forefront of what most people considered when talking about diabetes management, when asked to talk about what they had done to manage their diabetes, unless they reported no changes, participants would describe a dietary change they had made. Most often this would be related to cutting down refined sugar, followed by attempts to lose weight through diet. In order to enact dietary changes participants and those in the network responsible for food carried out a lot of coherence work which was mostly hidden, they developed a personal understanding of what is healthy and in what quantities. The participant then
tried to adhere to this diet with the support of their social network. Some participants fully normalised these changes while others were struggling to enact practices. The quotes below offer a range of how participants were managing their diet in light of the understanding they had developed and their pre-diagnosis practices and preferences. The first quote describes the struggles of one participant to find low sugar alternatives to the sweet foods which he and his wife enjoy:

“I’ve tried fruit, but I’m told 3 or 4 is not good. Have one banana instead of a banana, an orange, an apple and a pear; just have one. We’ve tried sugar free jellies, sugar free vimto, Horlicks light, all these light things, sugar free and it’s trying.”

(P16, male)

Participants or those shopping for them increased their attention to food labels and learned how to understand them. Some people found understanding them confusing and frustrating, others found the labels to be a useful guide. Many participants noted that food manufacturers put misleading portion sizes or other misleading claims on these labels and they became wise to this.

“What annoys me about the food industry and the moment is they’ll say 3% less fat. Less fat than what? 3% less sugar. They don’t tell you... When you see reduced fat or sugar you automatically think it’s good for you. You look at those labels and you’re having almost as much as you had before. Margarine or butter is the same, reduced fat. Reduced from what? It doesn’t tell you, it just leaves you thinking I’m being alright.”

(P19, Female)

This experience is echoed in the following quote:

“Absolutely, they’ve got away with murder, they’re a nightmare. You pay top dollar for it, you get home and you think this is worse than other stuff that’s half the price, you think you’re doing well and you’re not.”

(P16, male)
In summary, many participants found healthy eating to be a continued battle with learned behaviours, preferences, and temptations. They navigated this through various strategies including not buying contraband food and emotional work to comfort themselves when they are tempted. Those participants who were still using blood sugar monitors at the time of interview found them to be very useful to reinforce the consequences of negative behaviour.

6.5.4 Skill set workability

Allocation of tasks related to self-management support was passive in these interviews, support from family and friends was largely informal and undertaken without specific request from the participant. Support from healthcare professionals and other professionals was left to the professionals to organise.

Only healthcare professionals, other professionals and those responsible for cooking in the household had clearly defined roles in self-management support. Doctors and nurses deal with monitoring and medication and are expected to impart information. Other professionals do not feature so heavily in the interview. One participant received a lot of help through social services, this involved multiple people taking on defined roles in his care. This was arranged by the participant in conjunction with social services and his GP practice.

“The nurse comes here [inaudible] on a Friday. The chiropodist comes here. I want me hair cutting, there’s a woman that does that for me.”

(P4, male)

Tasks were often allocated based on traditional roles, with wives taking more of a caregiving role than husbands, although this was not true of cooking, as families appeared to assign this task to the person more appropriate. The assignment of tasks by gender was seen with children as well, with daughters taking on more of the practical support than sons.
“They’re all very good, I never try to call one of them really, I don’t like to do that, I cope on my own if I can. But they’re always around, I know they’re always there if I need them, especially my daughter of course, she gets the most of it really with being the only girl you know.”

(P23, female)

To summarise, information seeking work was spread throughout networks. For example the children or grandchildren of older participants sought information on the internet for the participant. The participants themselves took a great deal of responsibility for self-management.

6.6 Reflexive monitoring

6.6.1 Communal appraisal

Evaluation of the success of disease management largely happened between participants and either their GP or nurse. Because of the regular tests that people with diabetes have to monitor their condition, participants tended to get feedback about the success of their efforts through interactions with healthcare professionals. These were largely didactic, with the professional telling the participant whether they were doing well or not. This is particularly true of registering an HbA1c level of less than eight. Based on this, the professional might provide the participant with suggestions to improve their disease control, but some participants reported that they did not.

“The satisfaction is when you move my highest blood sugar level was 6.7 and now I’m 5.8 so I’ve moved but it gives me a certain amount of satisfaction that it’s come down from where it was to where it is”

(P24, male)

“the nurse used to, when I started on a low number and every morning she’d ring me and I’d tell her what me blood results are and then she might say tonight, I do it twice a day morning and night, tonight do it a bit higher. She kept doing that for about a week until eventually it got to what she wanted and that was it”

(P8, female)
Participants were encouraged by positive evaluation of their behaviour by those around them, as in the quote below.

“The people that live here have that explained to them. They might have a joke when I bring cake out say oh how can you do that. Especially if they are doing slimming and they want to slim and they eat a piece of cake and they look at me and they think oh I wish I had your control. It’s just something that you just get used to it.”

(P8, female)

6.6.2 Individual evaluation

For those who experienced them, physical symptoms were important in evaluating how effective their disease management was. Recognising the signs of high or low blood sugar allowed people to know when their practices were having the desired effect.

“I like chocolate, not, I’m a chocoholic or used to be. I tried to cut down with difficulty. You see any harm, you don’t feel any worse after having chocolate or a takeaway then it’s difficult to say ‘no, I don’t have to have that’ because you don’t feel any different after it.”

(P13, male)

“Oh yes, I get the pains and it reminds me... In my feet particularly. It's not so bad, it's me feet that start. I get a jab every so often”

(P5, male)

People also evaluated their behaviour against the behaviour of other people with diabetes in their social network. This was almost always positive for the participant as they compared themselves to the people who they knew who were not managing their diabetes well or who were in some way perceived as less healthy.
“Well as an example, there’s people I know similar to me, you follow their progress before we got together, and she’s in a bad way. She ignored it worse than me, you order Pepsi max, that’s the small changes you make, you quit smoking. She’s still on the fags, full fat coke on the go.”

(P13, Male)

“...he’s supposed to test his blood, but I don’t, I’ve not been asked to. So I must have a... It’s there but it’s a mild form perhaps. Perhaps taking metformin means it stays a mild form, but he just ... he doesn’t care about it.”

(P18, male)

“The first group there was nine of us, and considering I was twenty stone I looked around and I could see they couldn’t fit in the chair, I can understand how they’ve got it, I was normal. Obviously not because I had it, the way they looked I felt in good company on my own”

(P19, Female)

6.6.3 Reconfiguration

There are few examples of reconfiguration in the interviews. There are the strategies quoted above to ensure that medication was taken, repeated attempts to change diet in ways that are still pleasurable (quoted above).

“I didn’t work for years and then I started working October and it became very difficult then to maintain my diet. Er... from the point of view that my sugar was going low in the middle of the morning and things like that because you’re up early and um... you’re busy so you’re out and about um... so whatever you have for your breakfast er... whatever sugar content is in that starts to run out mid morning um... so you have to learn to cope with and um have a slightly larger breakfast than I would normally have to try and get through to lunch time. Where I’m working there is like a tuck shop so if necessary I could get to”

(P2, male)
For some participants repeated attempts to reconfigure their diet were not working so they felt like giving up. There are examples of this throughout this chapter and in the following quote, it was difficult for people not to become disheartened by the process of enacting lifestyle change.

“It is, when you speak to diabetic people and say what can I have, stay away from bananas, really, I thought they were good for potassium and vitamin B? Very high in complex sugar. I didn’t know that, can I have an apple, they’re not good for you. Why? They’re full of acid not good for your teeth and you’re stuck. You see your dietician again but he’s away for two months so you give up”

(P16, male)

Although most participants did not suffer from side effects caused by their medication, the participant speaking in the quote below did have problems with his medication which he changed with his doctor in an example of reconfiguration

“Plus he’s on Metfomin tablets, which don’t suit me... it was too strong when they put me on them, because they do use a lot of your food energy, so they took me off them and put me on glycoside and from glycoside they put me on injection”

(P26, male)

6.7 Normalisation

Participants in this study had normalised different practices to varying degrees. Almost all participants had managed to normalise having diabetes, it was only a cause of unhappiness in two participants, one because he was struggling with dietary change, leaving only one person strongly affected by his diagnosis.

“Um I it’s just something that I’ve just got used to living with basically. It doesn’t bother me. I don’t sort of regard it as what’s the word I’m looking for? Something I should be ashamed of or frightened of telling anybody, it doesn’t really affect me in that way, I’ve got it and that’s all there is to it. It’s a question of managing it and living with it and making sure it doesn’t affect my life unduly getting in the way of the things I want to do.”
“I wish I could motivate myself to be more physical than I am, I wish I could motivate myself to have the perfect diet, but again I don’t feel that I can. It’s like at the back of my mind, how should I do this? That’s what it is.”

(P5, male)

Taking medications was the easiest of the practices associated with diabetes management for participants to normalise. All participants had managed to integrate their medication regime into their lives, this was reportedly done with ease by most participants. Few participants needed to develop strategies to prevent missing tablets, by the time those participants took part in this study they had normalised these strategies.

Exercise and dietary changes yielded more mixed results. Many participants who wanted to enact change had managed to normalise dietary changes. Placing meaning on lifestyle change through shared and individual work to develop beliefs, rules and small changes such as reducing sugar were most likely to become normalised, whereas participants continued to struggle with larger dietary changes. Social support was very helpful to participants who were trying to embed these changes. Many participants had managed to successfully change their preferences and fully normalised their new practices

“I don’t have as many sweet things as I used to have because I had a sweet tooth at one time, but I’m more careful about it nowadays, but I got so used to it doesn’t bother me.”

(P23, female)

“Sugar. Actually sugar. Because I used to have a lot of sugar didn’t I, I have sweeteners now... In fact I don’t like sugar now, I’d sooner have sweeteners”

(P9, male)
“Well I stopped eating cakes and chocolate, I used to like. It's funny how you get used to not having it. When we're having afternoon teas here and stuff, I can cut the cake up and deal it out to people and it won't bother me not having a piece. I know sometimes you can have a little treat but it doesn't bother me. You lose your taste for it.”

(P8, female)

Others had managed to enact change, but without normalising the change

“I struggle with my diet because I like my food.”

(P19, Female)

Exercise tended to be fully normalised with participants taking regular walks or gardening as part of routine, or not a consideration (either the participant did not want to or was unable to due to comorbidities). There were few participants who wanted to exercise but had contextual barriers that were preventing them from doing so.

6.8 Themes outside the normalisation process theory

In order to facilitate the application of the NPT in this study loose definitions of the concepts were used, despite this there were still two themes which fell outside the NPT framework. These themes were balancing diabetes management with enjoyment of life and emotional eating. The first of these themes was very common throughout interviews. Arguably it could have been considered coherence or collective action (see 7.9.1), but the processing associated with balancing self-management with quality of life appeared did not quite fit with either coherence or collective action. People found balance in different ways, some mentioned above reduced pleasurable activities which they believed were not positive for managing their diabetes but which they still maintained to a certain level to enjoy their lives. Others made several changes, but refused to discontinue other activities. This process of making changes seemed to be largely emotional and later rationalised, rather than a mental process that would fit neatly into coherence. The quotes below demonstrate the balance that many participants talked about when talking about lifestyle change.
“Yeah I don’t drink, I don’t smoke, I exercise as much as I can. I started eating veggies, I eat occasional fruit so something’s got to give. I can go several weeks without crisps then suddenly I want 12. That’s life everyone gets a bit of that. Chocolate if I go more than a day I get cranky. 2 days I’m not nice. Third day I have a Mars bar. That sort of thing.”

(P20, male)

“Also sometimes I did go over board and I’d come around after a couple of days and realise that I need... to get it out of your system. Sometimes you think I fancy a drink and I do and then I realise and I stop it. This last week I’ve been on cake a couple of times, haven’t I, love?”

(P9, male)

“And if I do have a piece of chocolate, like one square and that’s enough, that fills me, as like a little treat I think if I just have one crisp, or I’ll just have one piece of chocolate, one square that seems to fill me I don’t want another one. At one time, before the diabetic, one square, then I’d have another and another.”

(P8, female)

The second theme which could not be encompassed by the NPT framework was the emotional aspects of eating. Participants who ate because they were upset, feeling generally low, or bored. Many participants did not feel that this was a problem for them, but for those who did it was a significant barrier.

“Yeah, especially when I’m pissed off, gone out for a walk and I’ll have three bars before I get back here, don’t feel any better for it... you’re used to feeling down and eating the crap foods that make you feel a bit better because they release all the endorphins, it’s only a temporary fix, you eat a couple of Mars bars to feel good, you do it every day and Mars bars won’t do it”

(P20, male)
6.9 Conclusions

This study highlighted many barriers, box 6.1 gives a list of the prominent barriers in this data. Using the NPT sensitised the analysis to social processes surrounding enacting diabetes management, without neglecting all individual processes. Looser definitions of the NPT concepts were applied to facilitate the use of the NPT in this study, please see chapter seven for further discussion of using the NPT in this context. A key benefit of applying the NPT was the theoretical links between thought, preparation, action and evaluation and that these interact in both forwards and backwards in time to result in normalisation or not. This was an ongoing process for most participants in this study. With the loose definitions of each concept applied most of the data could be coded inside the framework. Potential barriers to self-management existed at each stage of the theory, either through clear barriers, or the absence of facilitators. The following will summarise the findings of the study by concept of the NPT, as all the participants adhered to their medication regime the following barriers are focused on enacting lifestyle change.

**Box 6.1: Barriers**

- Poor understanding or not placing meaning on diabetes and self-management practices
- Resistance to self-management
- Belief that self-management practices infringe on quality of life
- Poor relationship with healthcare professionals
- Comorbid disorders which reduce mobility
- Those who had smaller social networks had less support to manage their condition
- The urban environment made exercise and accessing facilities more difficult or less appealing
- Low income acts as a barrier to access information, healthy food and sometimes a safe environment to exercise.

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Coherence: Understanding and placing meaning on diabetes and the practices associated with managing was strongly related to whether people choose to undertake lifestyle change, as predicted by the NPT. Developing an understanding that diabetes is a potentially serious condition, its potential complications and the practices that can prevent can prevent complications was achieved through discourse and individual processes. There was formal work in information seeking which was done by both the participant and family of the participant. Information was also received from healthcare professionals. Barriers associated with coherence were varied: there were participants who did not engage with learning about their condition or lifestyle change, there was probable misinterpretation of information from healthcare professionals. Some participants experience reduced access to information, either through financial barriers such as the cost of Diabetes UK membership, or lack of knowledge about the resources available, compared to more affluent participants in the study. The work done by family members to learn about the condition and how the condition was managed also allowed them to make positive contributions to self-management support. Participants for whom their family had made less effort to understand, or did not have close family, had less support to manage their condition at the collective action stage.

Cognitive participation: There was little talk of the preparation work described in cognitive participation, this is possibly because much of the work of self-management support is required by healthcare professionals or informal work conducted by family and friends. This means there is little need for developing relationships to facilitate self-management support. Another reason could be because of the length of time since diagnosis for all participants may mean that this work is in the past and no longer considered. Participants did talk about shopping, ensuring the correct foods were in, this was included in coherence for this study, but there is cross over with initiation. The work that was categorised as cognitive participation in this study was work done to prepare for possible consequences of diabetes, such as low blood sugar, or generalised health crises. Few participants thought about this and very few made preparations part of their routine, so it is hard to draw conclusions about barriers from this section.
Collective action: collective action is the largest section of this chapter. This encompasses all the enacting of practices, overcoming barriers and contextual barriers experienced by the participant. Disposal of work and the work of overcoming contextual barriers was linked to coherence in a variety of ways. There was a lot of work and contextual barriers described in the section so the following is an overview. Facilitators to this work included: social support, both practical support and emotional support; adequate access to tailored support from healthcare professionals; a safe environment to exercise. Barriers to self-management included a lack of the above as well as: not having the financial means to purchase healthy food, or living in an environment which makes it more difficult to obtain healthy food; demands placed on the participant by the social network which were inflexible.

Reflexive monitoring contained examples of participants changing the way they enact difficult tasks, but many participants discontinued difficult tasks if they felt they were not achieving their goals. It is possible that more support from healthcare professionals would enable people to better integrate their self-management practices into their personal conflicts. Participants often talked about people in their social network who were not managing their diabetes well. This was important emotional work for the participants, but also seemed to act as a barrier to putting greater effort into self-management by pointing out that other people are not doing as well as them. Social disadvantage was indeed a barrier at the most important stages of implementation in this study: coherence and contextual integration. Those who were less affluent or had fewer meaningful social relationships were at a severe disadvantage to those with more money or social connections.
7 Reflections on experience of using the normalisation process theory to identify barriers to self-management in type II diabetes

7.1 Introduction

This chapter will address the second aim of this study, which is to establish how useful the normalisation process theory (NPT) is when applied to individuals trying to implement practices in ‘open’ systems. This will be done by reflecting on the experience of carrying out the qualitative analysis in the context of the NT and trying to identify both positive and negative aspects of this. Previous researchers who have applied the theory to studies of individuals have reported that it was a valuable tool (Gallacher et al, 2011), but for this study the results were mixed. The NPT did help to highlight contextual and social barriers and facilitators, and the theoretical link between coherence and collective action was also helpful in identifying barriers. However, the theory was difficult to apply to the data; modified definitions were applied to the concepts to work with the differing contexts and increased importance of mental processes of a central individual situated within an open network. There were initial problems in applying the theory due to the complexity of the language used to describe the theory. Not all concepts, or sub concepts, were relevant to the context of this study.

7.2 Normalisation

For this study, defining ‘normalisation’ was not as simple as in the original contexts of implementation of interventions in healthcare systems, where whether or not practices are routinely undertaken is a simple assessment of normalisation. In the context of this study, participants chose different practices to undertake from a variety of recommended lifestyle changes; for example, some people had attempted to enact large changes to diet but had struggled to normalise them, whereas others had normalised smaller changes. Many participants had normalised their own interpretations of self-management, such as in the case of one participant who used several insulin injections a day to counteract the effects of his diet and alcohol consumption on his blood sugar. He had fully normalised this use of his medication, while some other participants believed that cutting out
alcohol was one of the most important self-management practices they had undertaken.

There was also the issue of normalisation of a diagnosis of diabetes; the majority of study participants appeared to have fully normalised having diabetes. However, other people appeared to deny or ignore the implications of the condition. It was difficult to distinguish between healthy normalisation and unhealthy normalisation (which included denying the seriousness of the condition).

7.3 Comprehension

A requirement of any theory or model is that it must be understandable by those who must apply it. In the case of health services research this is particularly important, as people from a variety of disciplines work in teams to conduct research. These disciplines include sociologists, psychologists, health service researchers, and clinicians amongst others, who must all be able to apply the theory with relative ease to aid uptake. The way in which NPT is presented in May and Finch (2009) meant that it was difficult to apply to this specific study. It required effort to interpret the theory before it could be applied to the study, both in developing the interview schedule and in analysis of the data. The language used to describe the theory is difficult for non-sociologists to comprehend. As stated previously, the academic background of the author is in psychology and health services research, and the language used to describe and explain the theory throughout much of the NPT literature was a distinct impediment to using the NPT in this study. Through extensive reading and research conducted for this study it was possible to come to an appropriate understanding of the theory to apply it in this study. However, in the environment of a normal study this level of exposure to the literature and dedication to developing an understanding of the theory to the exclusion of competing work would not always be possible. Personal communication with a variety of people either using the theory, or trying to come to an understanding of the theory highlights this as a problem experience by many people who could potentially use the NPT.
7.4 Coherence

For the purposes of this study, a working definition of coherence was “the individual and social processes which lead to understanding and placing meaning on diabetes and self-management practices”. The theoretical link between the work of placing meaning on the practices and ultimately enacting the practices was useful to identify potential barriers at the coherence stage, but it is just a theoretical link.

When placing meaning on self-management practices, emotions and beliefs were far more influential than the NPT would suggest. This is once again due to the differing context from learning about new practices in the workplace. People may have opinions about the workplace, but may be less likely to be emotionally invested, in comparison to self-management practices which affect their health, lifestyle and relationships.

7.4.1 Individual Specification

Using the NPT highlighted the practical work of information seeking and how different participants went about this.

The codes relating to “developing a personal understanding of diabetes and related practices” was used to catch a lot of different emotional reactions, individual differences and beliefs about the condition. As a result very broad and different concepts were classified together, and it is possible that in choosing this approach some subtleties in these codes were lost. For example, most participants asserted strongly that they managed their diabetes alone and that it was solely under their own control. This is relevant to both self-efficacy and locus of control but using the NPT does not highlight these concepts, meaning that both are assimilated into understanding the participant develops about the practices associated with diabetes management. It could be argued that potentially there would have been value in viewing these concepts as separate entities. There is also the problem that these well researched individual differences were never originally included in the concept of coherence, but only in the modified NPT applied to this study, bringing about questions as to whether they are relevant in an NPT analysis and whether the theoretical links made
between understanding and action can be ascribed to individual differences such as this.

It bears repetition that the NPT was developed to describe how changes made in the workplace are implemented. This is a very different context than the everyday lives of people, where people are making decisions and trying to implement practices outside the workplace and in their lives, and may be likely to make sense of these practices in a much more emotional way. Denial that diabetes is a dangerous disease appears to be emotional work, rather than part of an intellectual process of sense-making based on knowledge and experience. This appears to be the case in these interviews, some study participants stated that diabetes is not dangerous, based on their experience that it is uncommon to see amputees due to diabetes, or they expressed the view that people do not die from diabetes.

Another example of how many individual differences are compounded into this one concept of the NPT was that themes such as ‘rebelliousness’ could have been coded as an attitude had the theory of planned behaviour been employed as the theoretical framework. In this case, it might be more appropriate, so that the findings of this study more easily fit into the existing body of literature (see 3.3.4). Reconceptualising using NPT may have resulted in a loss of sensitivity to individual differences.

Coherence, as described in the original NPT, is an intellectual exercise by including emotional reactions and individual differences into coherence there is an element of “shoehorning” to make the data fit the framework in order to make the framework usable to answer the primary research question of this thesis. It could therefore be said that there was an artificial rather than natural fit between the data and the theory.

7.4.2 Communal Specification

Using the theory helped to sensitishe the analysis to discourse between the participant and members of their social network which allow them to enact self-management practices. The NPT also sensitised the analysis to work done by members of the social network to enable their own contributions to collective action.
Several participants were resistant to receiving information from other people, such as healthcare professionals, stating that they already had the knowledge they require. Applying the NPT framework to this data showed that this was happening, but not why it was happening. Understanding why is important in the context of this study to allow the data to help inform the development of new interventions. It would be unfair to lay the blame solely with the NPT framework for this particular problem as the data is somewhat ‘thin’ in places, but it is unclear where in the NPT there would be space for why people might be resistant to learning.

7.4.3 Differentiation

Differentiation was useful for understanding why certain types of changes, specifically small, defined changes such as cutting out sugar in hot drinks was easier than larger, vaguer changes such as eat more healthily. For the majority of participants to enact changes they had to have the changes that were well defined and substantially different from how they perceived their pre-diagnosis practices. In this example, the majority of participants felt that their current diet was healthy, and as a result many felt they had nothing to change. On the other hand participants could clearly define the difference between having sugar in tea and not having sugar in tea and that the latter was better for controlling their disease than the former.

7.4.4 Internalisation

This was a useful concept to describe knowledge and experience that had become part of the conscious decisions made by participants, but without the practices having become normalised in routine. An example is where dietary knowledge had been acquired and was being used as part of the decision making process, but where the actual dietary changes such as reducing fatty foods were still not fully normalised and remained difficult for the participant. This is in line with the original use of the concept in the NPT literature.
7.5 Cognitive Participation

As stated in chapter six (section 6.3), cognitive participation was the most problematic of the NPT concepts to apply. In this study there was little evidence of planning or developing relationships which aid self-management for the purposes of self-management.

7.5.1 Activation and Enrolment

Relationships that benefitted self-management tended to be in place and longstanding prior to diagnosis, primarily familial or social relationships which facilitated self-management through practical or emotional support, or by not acting as an active barrier (for example the cases presented in the previous chapter where friends and family members accommodated the needs of the participant in meal planning). Other relationships which aided self-management were formal relationships with professionals either in the health care system or other professionals such as social workers.

7.5.2 Initiation

The other facet of cognitive participation is planning. Arguably, the work that goes into shopping and planning meals could have been coded as initiation but the work of learning about diet and nutrition fell into individual or communal specification, and the work of enacting dietary changes fell into collective action.

Complicating the issue further, participants did not often identify planning their meals but rather tended to eat what they felt like eating on any given day. This, again, could mean that shopping for the correct food is a facet of initiation rather than a combination of coherence (learning about which foods to eat) and collective action (going shopping). In the context of this study, the data seemed to fit into the two above categories, but this is something which could have been debated further had the data been double coded.

7.5.3 Legitimation

The concept of legitimation was more complicated in this study than establishing a belief in self-management practices through acquiring and evaluating knowledge. Instead, legitimation involved complex patient-provider interactions
which influenced how participants viewed self-management practices. Whether or not participants had trust in their healthcare professional appeared to influence how they perceived self-management practices and how much importance the participant placed on the professional evaluation of self-management practices. This was true of both formal evaluation such as HbA1c levels and informal feedback such as the personal opinion of the professional about the self-management practices of the participant. In the context of this study, legitimation represented a complex social process. It would be useful to understand why certain healthcare professionals seem to enable legitimation of self-management practices and others do not.

7.6 Collective action

Collective action was the NPT concept which was most useful for extracting social and contextual barriers which may have been lost when using a theory more focussed on individual differences. Once again, the definitions used were slightly modified to fit the differing context of this study; these modifications were in line with the framework developed from the work of Blakeman et al (2012) and Gallacher et al (2011).

Across the entire theory there were lots of themes which came under more than one NPT concept; this was most common in collective action where the sub-concepts are interrelated.

7.6.1 Interactional Workability

For this study the majority of data relevant to interactional workability was in the disposal of work, or how work got done. Participants take so much of the burden of management on themselves (self-management) that little data existed about interactions with others such as family members about management and management practices outside of interactions with healthcare professionals. This meant that the code was something of a deviation from the original definition, but in line with the framework.

7.6.2 Relational integration

This concept was less relevant due to the fact that the relationships that facilitated self-management were most often already in place for some time or professional-
patient relationships. These relationships remained unchanged by diagnosis of diabetes and implementation of practices. There was one notable exception, in one case the wife of the participant left him following diagnosis, which was explained as being related to the participant’s wife’s fear of his possible mortality rather than the process of implementing self-management practices.

A benefit of using the concept of relational integration was that it revealed otherwise hidden work of community members in practical support of many participants.

7.7.2 Skill-set workability

Individuals operating in open systems do not have such clearly defined roles as people working in a closed system. There was evidence of skill-set workability in the data, this was mostly for professionals both in healthcare and in social services. Otherwise the majority of work (except cooking) was informal and not allocated to specific people.

7.7.3 Contextual integration

The majority of the work of collective action was coded as contextual integration. The concept as it is defined sensitised the analysis to a range of social and contextual barriers which could have remained hidden had a theory with a greater focus on individual differences been used.

7.8 Reflexive Monitoring

The value of reflexive monitoring and the sub-concepts was mixed in this study. There was loss of sensitivity to emotional processes, but hidden work was revealed.

7.8.1 Communal appraisal and individual appraisal

This was once again a stage where the emotional dimension is largely absent from the NPT; the evaluation process in the NPT is a rational process, and therefore the match with the qualitative data was imperfect – emotional reactions described by study participants were not captured by NPT. Participants often evaluated their own behaviour against that of other people with diabetes. In general, this was a person known to the participant who they felt was not
managing their diabetes as well as they were. The purpose of this comparative evaluation seemed to be to comfort the participant that they were achieving better management than the other person, or that they were not as sick as the other person. This did not lead to improved self-management; in fact, the choosing a friend who is struggling to manage seemed to excuse the participant from trying harder to manage their condition.

This is not to say there was no rational evaluation. Blood sugar monitoring was important feedback for participants in this study, they assessed all their efforts at disease management against this number whether it was a home blood sugar monitor or the HbA1c test that was taken by their healthcare provider.

7.8.2 Reconfiguration

Reconfiguration was a useful concept and highlighted some of the work that participants did to embed practices that were not working. This work was not always immediately obvious when coding and may have remained hidden had the NPT not been used to sensitise the data to such work.

7.9 Themes falling outside the normalisation process theory framework

7.9.1 Balancing quality of life

Efforts were made to fit all the data into the NPT to make the NPT as effective as possible to interpret data for this study some themes could not fit into the framework. One of these was the act of balancing enjoyment of life with managing diabetes. Clearly, this is not such a problem when implementing new interventions into a workplace setting, people are unlikely to be so invested in enjoyment in the workplace. However, in general, life enjoyment is important and diabetes self-management may be perceived as limiting certain enjoyable activities. Many people gain some pleasure from sugary or fatty foods, or alcohol. Similarly, many people gain enjoyment and relaxation from being sedentary. Or they find exercise unenjoyable. This means when it comes to managing diabetes participants did a lot of work to weigh up their health alongside enjoyment. None of the concepts could account for this work as it was a decision based not on rational pros and cons, but on preferences, emotions and individualised perceptions of quality of life.
7.9.2 Emotional eating

This theme was not common, in fact some participants expressly stated that their eating was not linked to their emotions. But for some participants eating through boredom, sadness, or stress was a problem in managing their condition. There was not an NPT concept to capture this fact. Once again, this is because the original context in which the NPT was to be applied was not as susceptible to emotional fluctuations.

The NPT assumes a group of people moving towards a goal in a rational manner, it highlights obstacles at each stage which could derail this endeavour. These obstacles are rational in nature, they look at information exchange, understanding, and contextual barriers. When applying the theory in the context of this study people have struggles beyond those rational and contextual obstacles.

7.10 Conclusions

With some modification the NPT was a useful framework for sensitising the data to social and contextual barriers to self-management. By examining the actions, and how the actions are planned and put into action both socially and individually, barriers to these actions come to light which may otherwise be hidden. However, this is at the expense of loss of sensitivity to individual differences. The concept of individual specification is particularly problematic for this loss of sensitivity. Carl May has suggested that it might be possible to link the NPT to the theory of planned behaviour, which could be used alongside the NPT to capture the aspects of individual differences which are missing from the NPT to make the theory more universally applicable (C. May pers com. Feb 2012). My own experience of using NPT leads me to conclude that further work in the field should be in the direction of linking and integrating the two theories rather than continuing to attempt to apply the NPT to the context of individuals implementing practices in their everyday lives.
8. Discussion

8.1 Introduction

This thesis set out to answer two questions:

1. what are the barriers to self-management of type II diabetes in a white, UK population,
2. Can the Normalisation Process Theory be used to interpret the findings concerning these barriers?

The methods employed were in-depth interviewing of a purposive sample, aiming to get a diversity of social conditions and to ensure that there was a good representation of relatively deprived people with diabetes. The normalisation process theory (May and Finch, 2009) was used to derive meaning from the data by applying a framework developed from the NPT.

Twenty six participants were included in the study. There was a high response rate to recruitment, this could be because the sample used to recruit from was composed of people who had already shown willingness to take part in research. Those who did decline to participate to cited time pressures or ill health as a reason not to participate. This could explain why it was difficult to recruit people who had jobs

8.2 Discussion of findings regarding barriers to self-management of types II diabetes

The primary aim of this study is to contribute to the understanding of what acts as a barrier to self-management for those with type II diabetes. The data collected identified a range of barriers to managing diabetes. Findings from the study are grouped into the following themes: individual barriers, social support, financial and environmental barriers, and interactions with healthcare professionals.

The majority of participants in this study believed that they were adequately managing their diabetes. Few participants knew their most recent HbA1c level, but for those that did, this belief was largely reflected by having a HbA1c level in the recommended range. However, there was evidence in the study population of complications resulting from diabetes, such as the presence of leg ulcers and
vision problems associated with diabetes, which suggest diabetes was not well controlled in all participants.

8.2.2 Individual barriers

This section deals with barriers relating to how participants enact self-management practices; how they attempt to overcome these barriers; how they perceive self-management practices and how they feel about those practices. This section therefore covers areas which are broader than the commonly identified individual differences such as self-efficacy and attitudes, although these concepts are important factors which are addressed.

Participants in this study found taking medication the easiest self-management practice to carry out, supporting previous findings reported in the section 3.3.1.4 of the literature review (Tang et al, 2008; Sharoni and Wu 2012 in Ahola and Groop, 2012; Ary, 1986 in Pun et al, 2009). They displayed positive attitudes towards taking medication and the effects of medication, more so than towards other self-management practices. By comparison, dietary change and exercise were often perceived negatively (results section 6.2.1). Expanding on the previous findings the recommended diet was often perceived as boring, or impossible to adhere to, whereas exercise was viewed as too difficult to carry out. Many participants felt that they were too old to exercise or that their comorbid disorders prevent any exercise. These concerns were also related to the theme of quality of life and balancing quality of life with diabetes management, such as believing that exercise would be unpleasant. People who had been prescribed insulin also reported adhering to their medication regime without much extra planning; interestingly, this finding contradicts results from the work of Egede and colleagues (2011 in Davies et al, 2013)

In contrast to previous findings (Davis and Renda, 2006 in Nam et al, 2011) participants in this study didn’t express fear of the physical nature of insulin as a drug, for example having to use injections (section 3.3.7.2). However, participants in this study did fear what insulin represented. Insulin was associated with type I diabetes which was perceived as a more severe form of diabetes. Participants believed that remaining on oral medication was an indication that their case of diabetes was not that serious. Amongst participants, there was
widespread confusion about what type I and type II diabetes are, what is the
difference between the conditions and what are the implications of having
diabetes (results 6.2.1 and 6.2.2). There was a belief shared by some participants
that poor type II diabetes management would lead to the disease progressing to
type I diabetes. This is particularly troubling because it may give people a false
sense that their condition is not life threatening as long as it is diagnosed as type
II diabetes. Supported by the reports of some participants that they did not
believe that diabetes was a serious condition (results 6.2.1). This may contribute
to denial based coping strategies which, as described above, have a negative
impact on self-management.

The use of the NPT concept of ‘differentiation’ (results 6.2.3) provided a prism
through which to assess why some changes are more palatable to participants.
People made small, distinguishable changes relatively easily, for instance
stopping sugar in their tea was the most common answer. The reason for this is
likely linked with perceived behavioural control and self-efficacy, in that
participants viewed these changes as ones they were capable of making with
minimal disruption to others. Differentiation describes these changes because
they are clearly described and distinct from current practices. This is contrast to
an aim such as to eat healthily; as most participants would describe their diet as
somewhat healthy to begin with, there is no difference from current practices. It
is worth noting that new practices that were considered too different from current
practices were dismissed.

The lack of formal planning for many participants in this study is interesting in
light of the findings of Kvam and Lyons (1991) regarding coping strategies, as
they found that those who displayed planning based coping strategies were more
likely to perform self-management practices than those who did not. Many
participants in study in this thesis did not plan meals or make contingency plans;
they tried to eat healthily but they did not go so far as formal meal planning,
valuing their preferences over health. A common theme throughout the
interviews was a perceived tension between quality of life and diabetes
management. Some people did plan in case of crisis rather than every day
planning, for example the installation of an emergency alarm (results 6.3.2).
As in the majority of the literature, in this study co-morbidities were perceived as a very important barrier to self-management, especially those conditions causing pain or fatigue (Wilkinson et al, 2014; Nam et al, 2011). Where co-morbidities were present managing diabetes was often relegated to a secondary concern with the focus on managing conditions which caused immediate pain and discomfort (results 6.4.1.1). This was not true of all conditions; for some people self-management practices for more than one condition overlapped and this provided motivation to enact practices. But even where there were overlapping needs for managing conditions co-morbid conditions could still act as a barrier, as in the case of a participant who found swimming prohibited following his heart attack. The complexity of the interaction between comorbid disorders and exercise emphasise the need for tailored support for people with diabetes to find styles of exercise which might be more suited to them where this is possible.

8.2.3 Social support

Section 6.4 of the results chapter described the many ways in which the social network affected self-management. It was difficult to get people to talk about the social network as a barrier, there appeared to be two main reasons for the reticence to discuss the social network as a barrier: the first is that people appeared to be uncomfortable implicating the people they cared about in something perceived as negative; second is that participants wanted to emphasise their own individual agency in all decisions regarding self-management (with exclusion of medication, which was considered the responsibility of the prescribing doctor).

Participants often seemed affronted and dismissive when asked about situations where the social network could influence poor self-management decisions, such as being asked about situations where they may be offered prohibited foods (cake) by friends or family. It is possible that the friends and family of participants in this study did not offer the participants prohibited foods, it is also possible that participants in this study had the self-discipline not to deviate from their diet plan. However, these findings would contradict other research in the field (Vanstone et al 2013, in chapter 3, section 3.6.1) which report that people with diabetes have more difficulty avoiding prohibited foods in social situations.
It is also possible that this situation does occur but participants do not perceive it in this way, believing that they always act with individual agency. This interpretation would be in line with the consistent assertions by participants in this study that they are solely responsible for their self-management and that nobody helps them or hinders them. When not asked directly, participants did describe ways in which the social network acted as a barrier, in indirect ways, such as having treats in the house for children or grandchildren which the participant then went on to eat.

The literature review in chapter three reports that participants without a supportive social network, or a network at all, are viewed as disadvantaged that they lack support for self-management (Pun et al, 2009; Murray et al, 2013) in section 3.6.1. This disadvantage is demonstrated across each of the concepts of the NPT; for example, in the case of communal specification (results 6.2.1), the social network supports self-management by helping participants to acquire knowledge about diabetes and related practices and by developing their own understanding of diabetes they place importance on self-management practices. This supports previous findings reported in section 3.3.4.2 of the literature review that having a partner that understands the importance of self-management may act as a facilitator to performing these practices (Ary et al, 1986 in Davies et al, 2013). It is likely that those who are already concerned about their diagnosis of diabetes will do more to learn about the condition. There is little said in the literature specifically about the role of children, though in this study, it is often the children of the participant who has sought information through the World Wide Web to support the participant. Gathering knowledge about either diabetes or related practices also prepares the network of the family to be effective in collective action.

In contrast to findings reported in section 3.4.3 of the literature review (Wilkinson et al, 2014) there was no evidence in this study of learning self-management strategies from other people with diabetes. This is partly because many participants did not like to discuss their condition with their peers. What they did report was judging the management of others negatively in relation to their own approaches to self-management of their diabetes. Making these unfavourable comparisons was reassuring to participants, but it did not promote a learning
process. It might be possible to argue that participants were learning how not to manage their condition, but as described by the participants in this study, participants are applying their knowledge to another person with diabetes and assessing them (see results 6.5.2).

In accordance with results from previous research (Lipton et al, 1998 in Nam et al, 2011) participants in this study often prioritised family commitments over their own self-management. As shown in section 6.4.1.2 some participants expressed a belief that to do otherwise would be selfish showing this belief exists outside the cultural contexts described in 3.3.5.5 of the literature review in chapter three.

Once again the tension between quality of life and self-management becomes important with participants in this study prioritising socialising with others through taking food and alcohol over controlling blood sugar (results 6.4.1.2). However, most study participants had attempted a compromise and had reduced their alcohol intake since being diagnosed with diabetes (although many of these participants attributed their cutting back on drink and food to getting older).

Partners, in particular women, were generally supportive of healthy eating, offering practical support by cooking appropriate meals and learning new cooking techniques, changing diet and offering emotional support (sections 6.4.1.2) Other practical support provided by the family and friends of participants include giving lifts, arranging medical appointments and doing shopping. Some participants reported that members of the social network would tell them not to eat certain foods. In their review Vanstone and colleagues (2013) reported that restricting and nagging where not as effective in supporting people with their self-management as most “positive” forms of support (literature review 3.3.4.1). This was not the case in this study and in general these methods of support were viewed with affection. The exceptions here were people who might be described as ‘rebellious’, and these participants were dismissive about all concern expressed by the social network (results 6.2.1).

Murray and colleagues (2013) found that company was an excellent facilitator for exercise and the results of this study reflect that, particularly the social aspects of dog walking
The findings that many participants reported that they found food labelling confusing or misleading is reported in the results chapter. People with diabetes have to learn how to interpret claims made on food labels in order to adequately manage their condition.

8.2.4 Interactions with healthcare professionals

The barriers associated with the NPT concept of ‘legitimation’ reflect and support the body of work examining patient-provider relationship affects how people with diabetes perceive self-management (reviewed in chapter three). Participants were more likely to value the opinion, knowledge and support of a healthcare professional that they felt they had a good relationship with. This was particularly true of healthcare professionals who were seen to “go beyond the call of duty” supporting previous findings (Wilkinson et al, 2014). This included giving the participant private access to them for support and treating the participant as important.

The results of the study show that at times there may be a breakdown of communication between healthcare professionals and participants. Many participants demonstrated a lack of basic knowledge about what diabetes is and why it is important to control the condition; these findings are in line with the work of other researchers reviewed in chapter three, section 3.5.2, demonstrating the differing understanding of diabetes and the risk of complications between healthcare professionals and people with diabetes. Lack of knowledge has been shown to be a barrier to self-management; what is unclear is why and how this lack of knowledge comes about. It may result from denial based coping strategies, poor communication, poor understanding or a combination of these factors. Previous research, in chapter 3 section 3.3.3 has shown that denial centred coping strategies are not associated with carrying out self-management practices (Gazmararian et al, 2009 in Ahola and Groop, 2012). There was evidence of denial as a coping strategy used by the participants in this study, such as minimising the risks associated with poorly controlled diabetes, and this reduced motivation to try to control the condition.

There is evidence of the benefits that tailored support can provide and this is discussed in detail in the case of one participant who received intensive weight
management support from a multidisciplinary healthcare team in the results chapter. She managed to lose more than ten percent of her body weight on this course, after which she had to leave the course. The benefits to this participant were great and she found leaving the course very difficult, since she started regaining some of the weight. The emotional and social aspects of the course were very important to this individual participant, a finding which supports what other research has shown concerning the importance of social support reviewed in chapter three section 3.6, and about tailoring support to the individual reviewed in chapter three (Wilkinson et al, 2013). The knowledge acquired during the course enabled this particular participant to enact self-management practices, but it was the social and emotional support that motivated her. From this case it is possible to see what may be achieved by offering a tailored programme of support which combines knowledge, social and emotional support. Where participants feel that the self-management support recommendations are not tailored to their needs (such as suggesting exercise groups to those who cannot perform the exercise as in results) they become demotivated. This is similar to research reviewed in chapter three section which showed barriers that occur where healthcare professionals do not consider cultural requirements when making self-management recommendations. It is all part of recognising the individual needs of the participants and how this is important in helping people with diabetes overcome barriers to managing their condition.

Many participants were demoralised by barriers which derailed their efforts at self-management. This was particularly so in connection with those practices which the participants believed would negatively affect their lives, such as dietary change. An example of this is participants who switched to fruit to accommodate sweet cravings, only to find out that too much fruit was also detrimental to their health described in results. This would demotivate the participant and they expressed feelings that it was too much to cope with.

8.2.5 Environmental and financial barriers

Access to care was reasonable for most participants in this study. However, those who did not have easy access to care had lower incomes and lived in urban areas. These participants could not see a doctor in a timely fashion, and often they were
unable to see their preferred doctor. This is possibly attributable due to the greater population density in cities. The urban environment, which was associated with the participants with lower income, was a consistent theme in the data. As described in the results chapter, living in urban areas which the participant deemed unsafe inhibited walking, the most common form of exercise reported by participants in this study. Those who lived in the more affluent semi-rural areas were more likely to report walking for health and pleasure. This was not true of people with dogs who went for daily walks regardless of their environment which is described in the results chapter. For participants in urban areas access to fresh food could be a challenge, many did not drive and relied on lifts, taxis and public transport to access supermarkets rather than driving. The participants from semi-rural areas all had access to cars making access to fresh food easier. From this it is clear that the environment and level of income, play an important role in self-management. These factors are often overlooked or neglected in the literature (reviewed in chapter three).

Employment acted as a barrier to those with jobs, described in the results chapter. Of the three participants in this study who were employed two were drivers, and this job prevented one from being prescribed the correct medication, the other from injecting insulin at the correct times and lead to participants feeling fatigued. A retired participant also speculated that appointment times for self-management support would be prohibitive to a person with a job. Like the environment, this is another contextual barrier which appears to be overlooked in the literature reviewed in chapter three.

**8.2.6 Evaluation**

Reported in the results chapter, the primary source of feedback on the efficacy of self-management efforts was HbA1c level but this was not the only source of feedback and evaluation. Social support contributed to evaluation in those participants who would discuss self-management or diet with their peers, for those participants positive feedback was motivating.
8.3 Findings relating to the use of the normalisation process theory to examine what prevents individuals from implementing new practices

Using the NPT helped to identify contextual and social barriers which may not have become apparent had a different method of analysis been employed. However, this was at the expense of individual differences. Given the importance in the literature attributed to individual differences described in the literature review, was something of a weakness in this study. The tension between quality of life and self-management practices ran through most interviews, it was a major barrier to self-management for participants in this study described in results. As discussed in seven it is to the detriment of the study that this barrier could not fit into the theoretical framework used to describe the findings.

In the results chapter, there are data where participants describe being resistant to knowledge. The data, which were collected using interview questions partly derived from the NPT, and the framework was not adequate for addressing why certain people were resistant to advice. This is because of the inadequacy of using the NPT to establish reasons for behaviour based on individual characteristics.

The major strength of the NPT framework was that it allowed for the identification of the environmental barriers which may have been overlooked had the NPT not been used in this study and are currently lacking from the literature reviewed in chapter three. In this study, employing the NPT to interpret data was both a strength and a weakness. On conducting the same, or a similar study, a theory such as the theory of planned behaviour (Ajzen, 1991) would need to be used in conjunction with the NPT to fully capture the barriers to self-management experienced by people with type II diabetes.

8.4 Conclusions

Quality of life was an important concern for people with diabetes. This meant balancing diabetes management with things they enjoyed (usually prohibited food or alcohol). This was only lightly touched on by the research reviewed in chapter three, but was one of the most persistently cited reasons in this study for not adhering to self-management regimes. It is possible that this is because it is hard for a healthcare provider to offer support on making the diabetes related lifestyle
changes seem appealing. It is an area for more work to develop tailored care for people with diabetes to encourage implementation of self-management practices.

The main contribution of this study was to provide greater understanding of the barriers to self-management of diabetes experienced by people who are socially deprived. Throughout the analytic process, it became clear that low income had an impact on self-management and that the associated barriers were more far reaching than suggested by the literature review. In line with the findings in chapter three, people on low incomes sometimes struggled with the cost of food, but many of the barriers were more subtle. Participants on lower incomes could not afford subscriptions to Diabetes UK or slimming clubs, both of which offer information relevant to self-management, and in the case of slimming clubs, social support. Participants with lower incomes experienced barriers caused by the very environment which they inhabit; these were diverse including: lack of access to shops (meaning the participant had mostly frozen foods); no safe areas to go for walks; more difficulty getting an appointment to see a doctor. This suggests that people with lower incomes are at a disadvantage in both developing an understanding of diabetes and related practices (coherence) and having the resources and opportunity to enact those practices (collective action).

The results of this study highlight the difficult barriers people with lower incomes must overcome to manage their diabetes. We can learn from the American experience described in chapter three that the erosion of the NHS will only make this struggle greater. The NHS should remain free at the point of service if it is to ensure that medication and self-management support is available to everyone.
8.5 Contributions of study

Box 8.1: Major contributions of study

- Supports findings of literature reviewed in chapter three relating to the importance of the social network
- Identified new barriers associated with living in an urban environment
- Identified barriers associated with employment
- Identified the role of quality of life as barrier to self-management practices relating to diet and exercise.
- Findings suggest that the NPT might contribute to future work in the context of individuals if it is used in conjunction with another psychologically orientated theory to give a more comprehensive understanding of how, and if, individuals implement practices.

The findings of this study supports much of the literature reviewed in chapter three identifying barriers to self-management of diabetes. Particularly the findings relating to the importance of social support in managing type II diabetes. The study expands on findings from existing research to identify many, more subtle barriers to self-management in type II diabetes, including access to healthy foods, information, employment, and the effect of the local environment on self-management. The findings show that for the study sample (a White British population of people living in Manchester and the surrounding area) diabetes management is at odds with perceived quality of life.

8.6 Limitations of the study

This study did not reflect the ethnic makeup of Manchester. The main reason for this is that the sampling strategy did not aim to specifically recruit people from ethnic minorities: as the pool from which participants were recruited was predominantly people of White British origin, this meant that the sample for this study was composed entirely of people who were White British. Were this study to be replicated efforts should be made to ensure ethnic diversity through purposive sampling.
The lack of results relating to individual difference is a limitation and was largely due to the analytic approach taken, that is to say, the use of the NPT as an analytical framework. On conducting the same study again a different or improved framework would need to be applied in order to address this. The importance of individual differences is clear from previous work described in chapter three and the fact that they are largely absent from the results of this study may be viewed as a weakness. This is not only because the NPT framework was used in analysis, which resulted in some coding of data in line with the NPT which may have been interpreted as individual differences using a different theoretical framework as a ‘lens’ for interpreting the findings. The NPT was also used to develop the interview questions so the NPT shaped the data in both ways. Interview questions did not just come from the NPT, the literature review also informed the questions meaning they were not limited to barriers which would fall into the NPT. This is evidenced by data which did not fit the framework described in chapter seven. There were also problems with some of the early data which was not as rich as would have been ideal resulting from an inexperienced interviewer, although this improved throughout the study with experience (please see personal reflections for more).

8.7 Recommendations for future research

Given the cost of treating complications from diabetes to the NHS emphasis should be on prevention of complications. Based on the findings of this study future avenues of research for new interventions should focus on social and emotional support alongside transfer of information. The participants in this study were very concerned about the effect of diabetes self-management on quality of life; as far as possible, so future research should aim to develop new interventions allow people to continue to take enjoyment in life. What makes these interventions more complicated is that they must appeal to both men and women, and be accessible to those from lower income areas.

8.8 Recommendations for policy

Resources should be focussed in areas of low income where access to self-management resources and healthcare are more limited
8.8 Personal reflections

Coming from an academic background of psychology and health services research with an emphasis on quantitative methods, taking on a qualitative study was a daunting task but one I was excited about. I have always seen the value of qualitative research, having recognised that survey studies can sometimes miss depth of understanding about why phenomena occur. But at the time of beginning this study I only understood how to interpret numbers. I had to develop an entirely new way of thinking about research and data, which was at times difficult, but very rewarding. I feel like a more rounded researcher, and a more rounded person for undertaking this research project. Despite initial nervousness at interacting with people in the interview setting, I found that I loved working directly with people. People have always fascinated me, which is why I studied psychology as an undergraduate, and qualitative research allowed me insight into why people behave the way they do. As in the case of diabetes self-management, why people sometimes do not make potentially lifesaving changes to their lifestyle is an intriguing question that requires further investigation. Using a sociological theory to explain this was also very new to me and at the time of starting this thesis my thinking was firmly rooted in individual differences. The impact of social support and the environment, although now clear to me, would not have occurred to me. To see so clearly how social inequalities are reflected in health first hand has deepened my desire to somehow address social inequality in my career.

Learning how to interview people was a steep learning curve, I went into my first interview with no experience and limited understanding of what makes a good interviewer. This was the first thing I had to do which I could not learn from a book to prepare me. I was lucky that people wanted to speak to me and many of the participants in this study made my job easier and more enjoyable by being good natured and open with me. I learned along the way that going in and asking direct questions did not give good interviews, this was reflected in the development of the interview schedule. But also that getting to know the participant a bit before the recorder was switched on resulted in better interviews, in particular that talking about a participant’s grandchildren would make them more happy and open with me. I also learned after a few interviews that letting
the participant in on a little bit of information about myself made them feel more comfortable. I found that mentioning my relationship with my grandmother, my own struggles with my weight and that my father has diabetes would put participants at ease and make them less defensive. Originally I would dress smartly for interviews but the more formal approach made participants uneasy, and after a few interviews I started attending dressed in everyday clothes. Along with these changes, and with coaching from my supervisors I developed a more relaxed, less direct interviewing approach, employing techniques such as waiting ten seconds after participant answers to give them time to expand. Together these adjustments resulted better interviews and data with more depth.

Not all interviews were easy, some participants did not want to talk to me. Some participants thought my questions were absurd and would audibly scoff. This was understandable as these people had been living with diabetes for some time and it was not at the forefront of their decision making. Interviewing participants who did not seem to want to talk was a frustrating experience, but I am pleased when I see that people who might not normally want to take part in research are represented in my results. However, I regret that the sample of participants was not diverse enough to include people from ethnic minorities.

Qualitative analysis was another new skill which I acquired during the process of this research project. I began with little knowledge or experience of qualitative research. Much time was spent trying to establish how to conduct and the benefits of different styles of data analysis. During the process I conducted several of these styles on transcripts before settling on framework analysis (Ritchie and Lewis 2003) which was favoured for making the NPT an integral part of the analysis. I enjoyed the process of finding themes in the individual narratives; one of the reasons I liked the process so much was that it put value on what people say and how they feel. It was sometimes a struggle to apply the NPT to the data, but over time and through careful analysis, themes in line with the NPT concepts did emerge. Although, as I say in chapter seven there was an element of fitting the data to the theory, especially in trying to find a place for the data attributable to individual differences. These data sat uncomfortably in the individual specification concept, but I believe greater emphasis must be placed on individual differences in order to make the theory more useful in the context of
individuals. Without the theory the results may have missed vital contextual barriers because learning about the NPT was integral to developing my understanding of the external forces on behaviour.

Coming from a more quantitative background, rigid rules for research rigor were the norm and it took some time to shift to a flexible understanding of quality in qualitative research, ultimately adopting a view that acknowledges researcher bias without condemning it and to understand then when researching how people perceive their social world must be less concerned with absolute truths, and more concerned with the truth as experienced by the participant.

The results from this study add to the literature regarding barriers to self-management in type II diabetes, particularly the literature regarding barriers to people who are from disadvantaged backgrounds, although many of the barriers were universal. In taking a broad view and letting participants identify their own barriers I believe I have expanded on and reinforced the existing knowledge.
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Appendix i

Interview schedule

Can you tell me a bit about your diabetes?

- When were you diagnosed?
- How were you diagnosed?
- How did you feel?
- What did you think?

Have you made any changes to your diet since you were diagnosed?

- Can you tell me a specific change?
- Some people cut sugar out of their tea, did you do anything like that?
- Did your doctor or nurse tell you to make any changes?
- Moderation
- Does anybody help you? Shop/cook/make decisions
- Understanding dietary change

Do you find there are times that keeping to your diet is more difficult?

- Family meals
- Out with friends
- Financial

Do you exercise?

- Walking/dog walking/cleaning
- Did you change anything after you found out you have diabetes?
- Does anything stop you exercising?
- Did your doctor or nurse talk to you about exercise?
- Do anybody encourage you/exercise with you?

How do you find taking your medication?

- Forgetting medication?
- Side effects?
- Ways to remember
- Do you know what your medication is for?

Do you find you get what you need from the NHS?

- Appointments
- Relationship with HCPs
- Understanding

Have you made any other changes that we haven’t discussed?

Have you had any other problems making changes that we haven’t discussed
Appendix ii

Normalisation process theory coding framework

These descriptions were developed from May and Finch, 2009; Blakeman et al, 2012; Gallacher et al, 2011

*Differentiation*: Being clear on the differences between old and new practices.
Being aware of participant’s own role and different HCPs role in enacting practices

*Communal specification*: Information seeking from other people (including HCPs) or by other people on the behalf of the participant
Developing an understanding of diabetes through discourse

*Internalisation*: Relating experience to diabetes and self management.

*Enrolment*: Engaging with others in the social network (including HCPs) to enable them to provide support with self management

*Initiation*: Using personal resources and skills to arrange contribution towards self management

*Activation*: Organising help from the social network (including HCPs) to undertake self management practices
Legitimation: Seeking reassurance about the efficacy of treatment and self management practices

Interactional workability: Enacting self management practices

Relational integration: Developing relationships with those who can aid self management

Overcoming barriers to accessing care

Skill set workability: Allocating tasks to those most able to do them

Contextual integration: Ensuring the resources are available (time, financial, social)

Integrating self management practices into social contexts

Reconfiguration: Changing the way self management practices are undertaken if they are found to be ineffective

Individual Appraisal: Individual evaluation of how effective self management practices and treatments have been

Deciding on an individual level whether or not to change self management practices

Communal appraisal: Discussing with members of the social network (including HCPs) whether or not to change treatment or self management practices
Systemisation: Developing ways to keep up to date with information on diabetes, self management practices and treatment