The Social Construction of Quality Diabetes Care Appointments in Primary Care by Adults with Mild-to-Moderate Learning Disabilities, Their Supporters and Healthcare Professionals

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The Social Construction of Quality Diabetes Care Appointments in Primary Care by Adults with Mild-to-Moderate Learning Disabilities, Their Supporters and Healthcare Professionals

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School of Health and Social Care

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Abstract

Questions have been raised over the quality of healthcare including primary care diabetes services for adults with learning disabilities. Despite numerous proposals and policies aimed at improving the quality of healthcare services for people with learning disabilities, little is known about what constitutes quality care from the perspective of key stakeholders.

This thesis aimed to: i) explore the social construction of ‘quality care’ in terms of diabetes primary care appointments by adults with mild-to-moderate learning disabilities, those who support their diabetes management and healthcare professionals; ii) reveal any similarities and differences in the ways in which these different stakeholders constructed quality care; and iii) explore the social construction of responsibility for the provision of quality diabetes care appointments for this population. A discursive psychological analysis was conducted on twenty semi-structured interviews: eight adults with mild-to-moderate learning disabilities and diabetes, seven supporters and five healthcare professionals.

The research demonstrated that different stakeholders drew on some common ideas to construct quality diabetes care appointments, notably that appointments should fulfil their purpose, stakeholders should fulfil their respective roles and responsibilities and that successful appointments are informed by medical and/or experiential knowledge. Stakeholders also drew on differential repertoires around the relationship between independence and quality diabetes care and practicalities and constraints in the provision of quality diabetes care. Different stakeholders were constructed as having different responsibilities. People with learning disabilities were often positioned as having a limited level of responsibility whilst others were positioned as accountable.

Quality care was flexibly constructed to perform identity management for the speaker, to attribute responsibility and to justify care which deviated from recommended quality guidance for diabetes care. Likewise, responsibility for quality care was flexibly taken up and attributed. The findings of this thesis have implications for ongoing discussions about the nature of quality care for people with learning disabilities in diabetes services and beyond.
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Chapter 1  Introduction

The concept of quality care is regularly raised in research and policy documents relating to people with learning disabilities, which often state the objectives of measuring and improving quality of care including healthcare for this population. How people with learning disabilities and other key stakeholders define quality care is currently unclear. This thesis examines the social construction of the concept of quality care specifically in relation to diabetes primary care appointments for adults with mild-to-moderate learning disabilities. It makes use of a qualitative methodology informed by patient and public involvement initiatives and is underpinned by a social constructionist framework. Accounts of the experience of diabetes primary care appointments were collected through semi-structured interviews with adults with learning disabilities, people who support them and healthcare professionals. Discourse analysis was employed to examine socially available discourses on quality diabetes care for this population and how speakers employed these to construct the concept of quality care. This thesis is built on the existing literature on quality health/diabetes care, the smaller body of research focusing on the experience and quality of diabetes care for people with learning disabilities and the minimal existing literature examining the social construction of quality in healthcare.

This chapter situates my thesis in the wider context of the current condition of healthcare for people with learning disabilities in England including healthcare policies relating to this population. It also sets out the epistemological position of social constructionism and critical discursive psychology which guided the research. I will end with a brief overview of the remaining chapters. First, I outline my own journey into this research, and how I came to focus on the topic of quality diabetes primary care appointments for adults with learning disabilities.

This study developed from a combination of my personal interest in diabetes, my work and academic experiences. My personal interest stems from my family background; although I do not have diabetes myself, I grew up in a family in which all members of my immediate and some of my extended family had type 1 diabetes. I have been involved in supporting family members in relation to their diabetes, including supporting attendance of appointments and structured education. Thus, discussions about diabetes including day-to-day diabetes management, complications of diabetes and experiences with healthcare professionals have been a regular part of my daily life for as long as I can remember. I became interested in how people with learning disabilities live with diabetes when the topic was raised in my work environment (a learning
disability research group) and during attendance of a conference on the social history of healthcare for this population. Discussions included the possible challenges of managing diabetes for people with learning disabilities and the roles of paid/family carers. The conference highlighted the extremely limited knowledge of the experience of diabetes care for people with learning disabilities and emphasised the need for research on this topic. This was against the background of reports and media attention highlighting poor healthcare and early morbidity for people with learning disabilities. In particular, the Mencap report *Death by Indifference* and the independent inquiry *Healthcare for All* (Mencap, 2012; Michael, 2008) informed conversation and research in the department in which I was working.

One of the many gaps in the literature on this topic centred on where responsibility for diabetes care is situated when the person with learning disabilities has a family or paid carer. This inspired my choice of topic for my Master’s dissertation module, which examined the social construction of responsibility for diabetes management by adults with mild-to-moderate learning disabilities and their paid/family carers (Rouse, 2014; Rouse & Finlay, 2016). This project indicated that both people with learning disabilities and those who supported them often positioned healthcare professionals in a peripheral role in terms of responsibility for diabetes management (Rouse & Finlay, 2016). During the interviews for this project, people with learning disabilities and those who supported them often recounted experiences with healthcare professionals including positive and negative encounters with GPs and practice nurses within primary care. These findings suggested that experience of diabetes care appointments, especially in terms of primary care settings, were an important area for further research. As described below, reports and policies at this time were setting out objectives to improve ‘quality’ care for people with learning disabilities. The interviews from my MSc project began to give some insight into what people with learning disabilities and their supporters might consider quality diabetes care. During a subsequent research project on an unrelated topic I learnt the value of including the voice of healthcare professionals in research on healthcare, motivating my inclusion of healthcare professionals within my thesis. My personal experiences therefore inspired my interest in furthering our understanding of diabetes care for people with learning disabilities. My work and academic experiences motivated me to focus on the perspectives of key stakeholders to investigate the idea of quality care in relation to diabetes primary care for this population.
1.1 The epistemological position

This thesis is based on a social constructionist theoretical framework. Social constructionism is based on the premise that our knowledge of the world is constructed between people in their daily interactions (Burr, 2015; Gergen, 1985; Sullivan, 2010). Thus versions of knowledge are not stable, objective, observable and measurable facts but are the result of social processes and interactions which vary historically and culturally (Burr, 2015). The construction of knowledge is bound with power relations, since how the world is constructed makes some social actions appropriate whilst excluding others. Accordingly, research from this perspective examines the social processes in which our shared understandings of the world are constructed, such as language. From this point of view language does not describe internal psychological states but is a form of social action, constructing our social and psychological worlds. Discursive psychology is therefore concerned with how people build accounts of events in their everyday interactions and the functions that these perform, such as building identities or defending a position (Burr, 2015; Edley, 2001; Sullivan, 2010).

Social constructionism has informed many approaches to research in the social sciences including the critical discursive psychological perspective taken by this thesis. Critical social psychology grew from a number of concerns by social psychologists, notably the need to critique the underlying assumptions of social psychology, and to aim for research which brings about social/political change (Burr, 2015; Hepburn, 2007). Since this project aims to inform improvements to diabetes care for people with learning disabilities it is located within a critical social tradition. Amongst the methodologies favoured by social psychologists working within a critical social framework is an approach to discourse analysis known as critical discursive psychology. Critical discursive psychology explores: how people build accounts of events and construct the world through language, the performative functions of language, the historically and culturally situated nature of talk and how dominant accounts may produce, sustain and resist power ideologies within society (Burr, 2015; Edley, 2001; Potter, 1996; Potter & Wetherell, 1987; Taylor, 2001b). The theoretical framework for this thesis is discussed in more depth in chapter 3 section 3.2.

Improving understanding of the ways in which key stakeholders socially construct quality and responsibility for quality diabetes primary care provision has the potential to inform and improve diabetes primary care provision. It may reveal social constructions that support good/poor quality care provision and highlight areas of similarity and mismatch between the constructions of
different stakeholders on what constitutes a good quality diabetes care appointment and who is responsible for ensuring this quality. Improved understanding of what people with learning disabilities and diabetes and their supporters construct as a quality appointment may inform changes to service provision in line with these views, which could support favourable evaluations of quality of diabetes care appointments and improved appointment attendance.

1.2 The wider context

1.2.1 Policy and guidance informing health and diabetes care for people with learning disabilities

This section briefly outlines the context in which the research took place in terms of health and social care policy in England for adults with learning disabilities and the ways these documents position key stakeholders in relation to the provision of quality health and social care for this population.

Inquiries, public pressure and high profile examples of failings in the healthcare of people with learning disabilities have led successive English governments to commit to improving the quality of healthcare for this population (Department of Health, 2001b, 2009a; NHS Improvement, 2018). The 2001 government white paper *Valuing People* (Department of Health, 2001b) and its associated reports (Department of Health, 2009a, 2009b) described the government’s proposals to improve the lives of people with learning disabilities, underpinned by the key principles of Rights, Independence, Choice and Inclusion (Department of Health, 2001b). This white paper described several objectives, including enabling people with learning disabilities to have as much choice and control as possible over their lives, support and services, and emphasised person-centred planning. Health related aims included: reducing health inequalities by improving access to services and healthy diet and exercise, ensuring people with learning disabilities could access a high standard of care designed around individual needs, and good quality services that promote independence, choice and inclusion and lead to good outcomes. Government policies on community services and support for people with learning disabilities also emphasise that people should have choice and control over how their health and care needs are met (NHS England, ADASS, & Local Government Association, 2015).

The *Valuing People Now* progress report (Department of Health, 2009b) described some headway in improving healthcare such as an increase in the number of people receiving annual health checks and use of patient passports. However, research has also highlighted the need for further
progress to improve access to and independence in healthcare including: increasing the numbers of people receiving annual health checks and better systems to identify people with learning disabilities in primary care services (Department of Health, 2009; Grant & Ramcharan, 2007). Barriers to implementing the health related goals of Valuing People have been reported including: lack of access to and poor understanding of the role of health facilitators, lack of health action plans, inadequate capacity of primary care practices to deal with health facilitation (Grant & Ramcharan, 2009). Furthermore, there has been a fall in the numbers of NHS learning disability nurses in England in the last decade (Royal College of Nursing, 2019).

More recently the learning disability improvement standards for NHS Trusts (NHS Improvement, 2018) have set out aims to support providers to give financially sustainable, safe, high quality, compassionate care within local health systems. This document states that people with learning disabilities and their carers should expect care from NHS services to be safe and personalised with equal access and outcomes. In order to deliver high quality services to people with learning disabilities all Trusts should meet standards which focus on: respecting and protecting rights, inclusion and engagement, and workforce development. Like Valuing People (2001), these standards are informed by a rights-based approach including human rights to life, freedom from degrading treatment and freedom from discrimination. Healthcare professionals must respect rights to autonomy by seeking free and informed consent to care and treatment and by helping people to understand their rights. Similarly, guidance on applying the NHS policy All Our Health to people with learning disabilities (Public Health England, 2018) emphasises the right to person-centred and equal effective care. It sets out core principles for healthcare professionals including considering capacity for every decision or action and working with the key principles of the Mental Capacity Act (2005) England and Wales (from here on referred to as the Mental Capacity Act). It also emphasises that making reasonable adjustments is a legal responsibility which should be embedded in everyday practice. Additionally, the NHS Long Term Plan for England (NHS England, 2019) describes plans to improve healthcare for people with learning disabilities, including improving understanding of the needs of people with learning disabilities through staff training.

Evidence of inequitable healthcare for people with learning disabilities including avoidable deaths and accusations of institutional discrimination within the NHS (Mencap, 2012; Michael, 2008) led to increased monitoring and recording of the health of this population, including setting up the Improving Health and Lives Learning Disability Public Health Observatory (now part of Public Health England) (National Development Team for Inclusion, 2019; Public Health England, 2017) and the Learning Disability Mortality Review (LeDeR) programme (University of Bristol, 2015). These bodies aim to improve the quality of healthcare for people with learning disabilities and
reduce health inequalities. The National Diabetes Audit also began to record and publish data from general practices relating to diabetes and people with learning disabilities (NHS Digital, 2017).

1.2.2 Guidance on diabetes for people with learning disabilities and diabetes

In recent years there has been an increased attention to improving diabetes care for people with learning disabilities leading to the development of guidance documents such as the NHS RightCare Pathway for people with learning disabilities who have diabetes (Diabetes UK, 2018; Kachika, 2017). These documents emphasise the importance of making reasonable adjustments to improve diabetes care through equitable access to optimal diabetes services. Responsibility for ensuring this is positioned primarily with commissioners but also with healthcare professionals and carers (Kachika, 2017). Support workers in social care settings are described as having responsibility for ensuring health needs are met by developing links with healthcare professionals and implementing health promotion initiatives (Kachika, 2017).

Key documents informing health and social care practice for people with learning disabilities and diabetes therefore focus on the need for high quality, person-centred, equitable care that fulfils legal requirements, including: the requirement to make reasonable adjustments, upholding of human rights, and consideration of mental capacity. People with learning disabilities are strongly positioned as entitled to the same human rights, legal protection and healthcare as people without learning disabilities. Additionally, they are described as entitled to independence and choice in their healthcare decisions and their daily lives. These documents often also position people with learning disabilities as ‘vulnerable’ and in need of protection and support to ensure equitable access to health services, good health outcomes and respect for their human rights. Commissioners, primary care trusts, healthcare professionals and social care staff are positioned as responsible to protect these rights and enable people with learning disabilities to access equal healthcare, promote healthy lifestyles and to support independence and choice in their healthcare decisions. Policy documents and guidelines, including those focused on diabetes care for this population, position healthcare services as responsible for making reasonable adjustments to ensure equal accessibility and quality of health and diabetes care for people with learning disabilities (Diabetes UK, 2018; Kachika, 2017). The amount of awareness and impact of these policies on the practice of healthcare professionals and social care staff is currently unclear.
Healthcare services and people with learning disabilities

The literature on health and healthcare services for people with learning disabilities has investigated the state of healthcare for this population focusing on equality and quality of primary, secondary and specialist services (Michael, 2008; Parliamentary and Health Service Ombudsman and Local Government Ombudsman, 2009; Turner & Robinsin, 2011). Authors have also developed recommendations and described and evaluated initiatives aimed at improving healthcare for people with learning disabilities including health promotion, structured education programmes and reasonable adjustments of services to the needs of the individual (Glover & Evison, 2012; Lindsey, 2002; Taggart, Truesdale, Dunkley, House, & Russell, 2018). Good practice has been reported in which services have given person-centred care and provided reasonable adjustments to services, such as the provision of ‘accessible’ information (Hatton, Roberts, & Baines, 2011; Public Health England, 2016c, 2016a). The Learning Disability Mortality Review (2018) notes that a third of cases reviewed for 2018 gave one or more examples of best practice in the areas of effective inter-agency work, person-centred care and end of life care (Miranville, 2019). The review states that best practice care is the care that everyone should expect. However, there is evidence that adults with learning disabilities in England experience poor health compared to their non-disabled peers and experience inequalities in their experience of and access to healthcare (Emerson & Hatton, 2008; Heslop et al., 2013).

Studies of GP data reveal high levels of unmet physical and mental health needs and poor general health (Emerson & Baines, 2011). British adults with learning disabilities have poorer health than non-disabled peers on indicators such as self-rated health, morbidity, cancer, diabetes, obesity and lung function (Emerson, Hatton, Baines, & Robertson, 2016). They also have low uptake of health promotion and screening activities, higher prevalence of psychiatric disorders, epilepsy and diabetes and poor dental care (Emerson & Baines, 2011). Key determinants of health inequalities for this population include: greater risk of social determinants of poor health (poverty, unemployment), increased risk associated with genetic and biological cause of learning disability, communication difficulties and reduced health literacy, risky behaviours such as poor diet and difficulties accessing healthcare provision (Emerson & Baines, 2011). Higher mortality rates and higher incidence of deaths potentially amenable to healthcare interventions have also been found for people with learning disabilities compared to the general population in England (Glover, Williams, Heslop, Oyinlola, & Grey, 2017; Hosking et al., 2016).

Reviews, inquiries and explorations of available data have revealed inequalities in healthcare for people with learning disabilities. Concerns have been raised in multiple areas of care, including:
delays diagnosing and treating illness, poor coordination and communication between different health services and other agencies, problems with medication and equipment, insufficient attention to and poor understanding of the requirement to make reasonable adjustments, limited knowledge and experience by health service staff of learning disabilities, lack of knowledge about the legislative framework and failure to work with or listen to family and carers (Heslop et al., 2013; Heslop & Hoghton, 2018; Mencap, 2012; Michael, 2008; Miranville, 2019). People with learning disabilities are also more likely to experience potentially preventable hospital readmissions (Kelly et al., 2015). They are also more likely to experience emergency hospital admissions for ambulatory care sensitive conditions which should usually be avoided through effective management in primary care including admissions related to diabetes (Glover & Evison, 2012).

Reviews and inquiries have indicated that legislation which should protect people with learning disabilities from inequalities in healthcare including the Equality Act (2010) which requires reasonable adjustments to be made, and the Mental Capacity Act (2005), are not well understood or adhered to by healthcare services and professionals and that there is particular confusion around capacity to consent (Heslop & Hoghton, 2018; Mencap, 2012; Michael, 2008; Miranville, 2019). Mencap (2012) argue that this has led to inappropriate use of Do Not Resuscitate orders, flawed best interest decision-making and the withholding of treatment justified through concerns about consent (Mencap, 2012). Failure to address inequalities is a breach of statutory responsibilities by NHS Trusts (Turner & Robinson, 2011).

1.2.4 Primary care services for people with learning disabilities

Primary care services play an important role in the health of people with learning disabilities (Carey et al., 2017; Department of Health, 2001b; Michael, 2008; Miranville, 2019). People with learning disabilities in England are more likely to consult in general practice than the general population (Carey et al., 2017). As the first/main point of contact for health promotion and most healthcare and treatment, primary care services are key to ensuring that people with learning disabilities can access quality health services (Department of Health, 2001b).

Nevertheless, concerns have been highlighted about the accessibility and quality of primary care for this population (Carey et al., 2017; Michael, 2008; Miranville, 2019; Nocon & Sayce, 2008). Authors have cited evidence of poorly managed medical conditions, poor general health, higher levels of emergency hospital admission, low involvement/exclusion from screening programmes, and accessibility and equality issues as evidence of failures on the part of primary care services to
offer accessible services that meet the needs of this population (Carey et al., 2017; Glover & Evison, 2012; Michael, 2008; Webb & Stanton, 2009b). A study of general practice data in England reported that people with learning disabilities were less likely to have longer consultation times and experienced lower levels of continuity of care compared to the general population (Carey et al., 2017). The report *Healthcare for All* (2008) stated that there was a striking lack of awareness of the health needs of people with learning disabilities within primary care services (Michael, 2008) and recommendations for improving healthcare for this population often target general practices (Glover et al., 2017; Heslop & Hoghton, 2018; Michael, 2008; Miranville, 2019).

People with learning disabilities, carers and healthcare professionals have also reported barriers to accessible equitable and quality primary care. These include: negative attitudes and lack of understanding from healthcare professionals, not feeling listened to, difficulty making appointments, inaccessible information, incomprehensible communication, feeling nervous and anxious about long waits and diagnostic overshadowing (physical health problems attributed to the learning disability) (Brady & Bollard, 2009; Dimensions, 2019; Healthwatch Derbyshire, 2015; Nocon & Sayce, 2008). Survey studies have reported primary care staff concerns over: lack of experience, training and confidence with people with learning disabilities, difficulty gaining a complete history, time consuming examinations, patient distress, ethical dilemmas around lifestyle issues (e.g. overeating), communication difficulties, uncooperative carers, non-attendance of appointments or not taking regular medication, consent and medical decision-making, inconsistent communication and unclear boundaries across services, and regular changes in carers (Brady & Bollard, 2009; Healthwatch Derbyshire, 2015; Powrie, 2003; Webb & Stanton, 2009b). Despite some evidence of good practice, the recent Learning Disability Mortality Review for 2018 indicates continued challenges for primary care services for this population, including: accessibility, non-adherence to the Mental Capacity Act and lack of learning disability awareness training amongst healthcare professionals and staff (Miranville, 2019). Furthermore, a recent UK online survey reported that people with learning disabilities and autism were 30% less likely to feel listened to by their GP than the general population and that 60% of people with learning disabilities and autism said that their GPs have not made reasonable adjustments to meet their needs (Dimensions, 2019).

Although some research and guidelines provide insight into the experience of diabetes care services for people with learning disabilities and other stakeholders (Brown et al., 2017; Care Quality Commission, 2016; Maine, Dickson, Brown, & Truesdale, 2018), research to date has not focused on the question of quality primary diabetes care from the perspective of key stakeholders. Given the importance of primary care in determining the quality of healthcare for people with learning disabilities and the key role of primary care services in diabetes care,
furthering our understanding of primary care diabetes appointments for this population is an important goal for research.

1.3 Understanding diabetes care and ‘learning disabilities’

In this section of the review I will consider what is described in the literature as the purpose of diabetes care appointments and explain why it is particularly important to further our understanding of the experience of these appointments for adults with learning disabilities.

1.3.1 Diabetes

Diabetes is a chronic condition in which insulin, a hormone that allows glucose to enter the body’s cells so that it can be used as fuel, is either no longer produced by the body (type 1), is produced in insufficient quantities, or works inefficiently (type 2) (Diabetes UK, 2019e). Levels of glucose in the blood therefore become too high and so must be controlled through a combination of diet, exercise and medication. There are two main types of diabetes: type 1 and type 2 (Diabetes UK, 2019e). Type 1 diabetes is the result of insulin producing cells being destroyed by the body’s immune system; explanations for this are currently unclear and it cannot be prevented, whereas type 2 diabetes is influenced by multiple risk factors including lifestyle (Diabetes UK, 2016b). Management of diabetes is complex and involves mastering practical and cognitive skills such as balancing blood glucose levels and level of carbohydrates eaten, and regularly administering insulin and/or other medications (Diabetes UK, 2015b) as well as managing the socio-emotional demands of living with the condition (Hinder & Greenhalgh, 2012a).

1.3.2 Defining ‘learning disabilities’

Learning disability is commonly defined as impairment in cognitive and social functioning apparent from childhood, including reduced ability to understand new or complex information and to learn new skills, which impacts on the ability to adapt to the demands of daily life (Department of Health, 2009a; The Foundation for People with Learning Disabilities, 2015; World
Health Organisation, 2014, 2017). Disability is often further categorised as mild, moderate or severe according to IQ level and/or adaptive function and support needs (British Institute of Learning Disabilities, 2016; Hatton, 2012; Mencap, 2015). It has been argued that learning disability is a socially constructed label defined and measured in varying ways according to factors such as professional judgement of best interest, financial, political, ideological and administrative considerations (Finlay & Lyons, 2000a; Hatton, 2012). A number of studies exploring diabetes management for people with learning disabilities do so as part of a wider sample of people with developmental disabilities/disorders. The term developmental disorder is used to cover impaired or delayed function related to the maturation of the central nervous system originating in childhood and persisting into adulthood (World Health Organisation, 2014). Although this term includes people with learning disabilities it also covers developmental disorders such as cerebral palsy and autistic spectrum disorders which are sometimes but not always characterised by a level of impaired cognitive functioning (World Health Organisation, 2014).

The term ‘Learning disabilities’ is used throughout this thesis. Language continually evolves and there is no comprehensively agreed upon term or definition to describe this population (intellectual disability, learning difficulty/disability), and different individuals and organisations have expressed a preference for different terminology. The term ‘learning disabilities’ is used by the Department of Health and cited by the Foundation for People with Learning Disabilities (Department of Health, 2001b; The Foundation for People with Learning Disabilities, 2015) and other major charities (BILD, Mencap).

1.3.3 Diabetes and People with Learning Disabilities

Although exact prevalence rates are unknown, studies internationally and in the UK indicate higher levels of type 1 and type 2 diabetes in people with learning disabilities than in people without learning disabilities (Anwar, Walker, & Frier, 1998; Balogh, Lake, Lin, Wilton, & Lunsky, 2015; NHS Digital, 2018c; Straetmans, van Schrojenstein Lantman-de Valk, Schellevis, & Dinant, 2007). Data from UK general practice records of diabetes amongst people with learning disabilities began to be made available in 2015. Based on data from participating general practices, Public Health England, NHS Digital and The National Diabetes Audit all describe a higher prevalence of diabetes in people recorded as having learning disabilities (Glover, 2016; NHS Digital, 2018a, 2018c). For example, Public Health England reported that using data from 36% of general practices in England, diabetes was recorded at almost double (1.9 times) the frequency in
patients\(^1\) with learning disabilities than in patients without learning disabilities (Public Health England, 2016b). In England 2014-2015 there were 65.2\% more people with diabetes among people with learning disabilities than expected in the general population allowing for age and sex profiled differences (Glover, 2016). The National Diabetes Audit 2016-2017 reports the prevalence of learning disabilities as around 40\% more common in people with diabetes than in the general population (NHS Digital, 2018c).

Higher prevalence rates of type 1 diabetes have been linked to chromosomal conditions such as Prader-Willi Syndrome, Down’s Syndrome and Klinefelter Syndrome (Anwar et al., 1998; Bergholdt, Eising, Nerup, & Pociot, 2006; Butler et al., 2002; Gravholt, Jensen, Høst, & Bojesen, 2011). Increased prevalence of type 1 diabetes has also been described in people with autistic spectrum conditions (Flygare Wallén, Ljunggren, Carlsson, Pettersson, & Wändell, 2017; Freeman, Roberts, & Daneman, 2005). This is part of a wider susceptibility to autoimmune disorders in these populations, explanations for which are a matter of debate (Anwar et al., 1998; Bergholdt et al., 2006; Butler et al., 2002; Freeman et al., 2005; Rohrer et al., 2010). Since propensity for weight gain/obesity (risk factors for type 2 diabetes) are characteristic of Prader-Willi Syndrome (which is characterised by increased appetite and excessive eating) and Down’s Syndrome, people with these syndromes are at increased risk of developing type 2 diabetes (Butler et al., 2002; de Winter, Bastiaanse, Hilgenkamp, Evenhuis, & Echteld, 2012). Increased prevalence of type 2 diabetes has also been described in people with Klinefelter and Williams Syndrome (Gravholt et al., 2011; Masserini et al., 2013; Pober et al., 2010). It has been suggested by some authors that the increased incidence of diabetes in these populations is related to lifestyle as a result of disability rather than as a result of the syndrome/developmental disability itself (Flygare Wallén et al., 2017). The wider population of people with learning disabilities are also vulnerable to risk factors for type 2 diabetes such as a sedentary lifestyle, poor diet, use of antipsychotic drugs, low socioeconomic status and obesity, and have been found to experience earlier onset of the condition (Dunkley, Tyrer, Gray, et al., 2017; Emerson, Baines, Allerton, & Welch, 2011; Glover, 2016; Taggart, Brown, & Karatzias, 2014). For example, the STOP diabetes cross-sectional screening study, which collected data on 675 adults with learning disabilities in Leicester, found that 68\% of their participants were overweight or obese, only 30\% ate the recommended daily five fruit, vegetables or salad and around half reported spending ‘a lot’ or ‘most/all’ of the day sitting (Dunkley, Tyrer, Gray, et al., 2017). Within the learning disabled population some variation in prevalence of diabetes has been associated with demographic factors, for example, women

\(^1\) Some people with diabetes may object to the word patient since it could suggest the person is passive in their diabetes care (Cooper et al., 2018). Where the word patient is used in this thesis it is intended to be descriptive of the context of people with diabetes in clinical encounters or categorisations by speakers.
with learning disabilities are at greater risk of developing type 2 diabetes than men with learning disabilities (Flygare Wallén et al., 2017; Public Health England, 2016b).

A comprehensive study of the incidence of diabetes in people with learning disabilities has not been completed and so reported prevalence rates vary. Studies conducted in the UK have reported prevalence rates of diabetes amongst people with learning disabilities within their specific samples ranging from 2% to 25% (Butler et al., 2002; Emerson et al., 2016; Frighi et al., 2011; Kerr et al., 2003; Shah, Bruce, Willson, Malik, & Gaffney, 2006). There are a number of difficulties with the data on prevalence of diabetes for people with learning disabilities. Data from UK general practice records includes only data from participating general practices and is dependent on the accuracy of GP records on whether a patient has learning disabilities (Diabetes.co.uk, 2016b; Public Health England, 2016b). Studies have used different inclusion criteria and sample sizes, focused on different populations and used varying sources of data. International studies may be further influenced by differences in healthcare provision and the characteristics of the general population (Flygare Wallén et al., 2017). Nevertheless, there appears to be agreement that diabetes is more common in people with learning disabilities.

1.4 Research Questions

Informed by the gaps in existing research described above, my thesis aims to answer the following research questions:

1. How do adults with mild-to-moderate learning disabilities and diabetes, those who support their diabetes management and healthcare professionals discursively construct quality diabetes care appointments during accounts of the experience of diabetes care appointments?

2. What similarities and differences are there in the ways in which different stakeholders discursively construct quality diabetes care appointments for adults with mild-to-moderate learning disabilities?

3. How do adults with mild-to-moderate learning disabilities and diabetes, those who support their diabetes management and healthcare professionals discursively construct responsibility for the provision of quality diabetes care for adults with learning disabilities during accounts of the experience of diabetes care appointments?
1.5 Overview of Chapters

This section summarises the chapters of my thesis.

**Chapter 2. Literature Review**

This chapter reviews and critiques the existing literature highlighting gaps in the research on which my research questions were built. It begins by reviewing the literature which indicates that quality diabetes primary care for people with learning disabilities is an important topic for exploration. The existing literature on the experience of diabetes care for this population from the perspective of key stakeholders is then examined. Finally, definitions and assessments of the concept of quality diabetes care for people with and without learning disabilities are considered and a case is made for the value of a social constructionist approach to this topic.

**Chapter 3. Methodology**

The methodology chapter begins by outlining the social constructionist theoretical framework on which this thesis is based and makes the case for the use of critical discourse analysis. The rationale behind my study design and methodological procedures is then outlined. The steps involved in recruitment and data collection are explained and details of participants described. Ethical issues are highlighted, and steps of data analysis described. The chapter ends by describing quality checks and considering feedback on the study’s impact received during data collection and presentations.

**Chapter 4. Findings chapter i) The construction of quality diabetes primary care appointments by adults with learning disabilities**

This is the first of three chapters which present my analysis of my data, evidenced with illustrative quotes. This chapter focuses on the analysis of eight interviews with adults with mild-to-moderate learning disabilities. It addresses my research questions by exploring their constructions of quality diabetes care in relation to primary care appointments, including examination of the roles and responsibilities of stakeholders in relation to quality care. It looks at the socially available discourses that speakers drew on to construct meanings of quality care, how quality of care was assessed and how people with learning disabilities positioned themselves and other stakeholders in constructing the quality of their appointments.
Chapter 5. Findings chapter ii) – The construction of quality diabetes primary care appointments by people who support adults with learning disabilities

This chapter presents the analysis of six interviews with people who have experience of supporting adults with mild-to-moderate learning disabilities in relation to their diabetes primary care appointments. Like the previous chapter, it addresses my first research question by exploring how speakers constructed the concept of quality diabetes care in relation to primary care appointments and how self and others were positioned in relation to these. It also examines discursive construction of roles and responsibilities in relation to quality care. This chapter further highlights similarities and differences in the discourses drawn on and the way they were employed by supporters compared to people with learning disabilities addressing my second research question as outlined in section 1.4.

Chapter 6. Findings chapter iii) – Healthcare professionals’ constructions of quality diabetes primary care appointments for adults with learning disabilities

The third and final analysis chapter examines findings from five interviews with healthcare professionals with experiences of clinical encounters with adults with diabetes and learning disabilities within primary care. Like the previous data analysis chapters, it explores the social construction of quality care and responsibility for quality care by these stakeholders and the positioning of self and other stakeholders. This chapter further examines differences and similarities in the social construction of quality care by different stakeholders, further addressing my second research question described above.

Chapter 7. Discussion

This chapter examines findings on the main interpretative repertoires and subject positions drawn on by participants to construct the concept of ‘quality care’ in diabetes primary care appointments for adults with mild-to-moderate learning disabilities. It then considers relevance to the existing literature on diabetes care and people with learning disabilities and the literature on the discursive construction of learning disability and diabetes care. How this thesis contributes to our understanding of discursive devices and their functions in relation to quality care is also discussed.

This chapter also describes similarities and differences in the discursive resources commonly drawn on by different stakeholder groups and the possible explanations for these. Implications of the available and dominant discursive repertoires and ways in which they were managed for quality diabetes primary care for this population are also considered.
Chapter 8. Conclusion

This chapter starts by summarising my findings in terms of my three research questions. It then considers the methodological strengths and limitations of my thesis, discusses implications of my findings for policy and practice and make suggestions for future research arising from this thesis.

1.6 Summary

This chapter has situated my thesis within the tradition of critical discursive psychology informed by a social constructionist perspective. My thesis was produced within the wider context of evidence indicating that healthcare, including diabetes care, for people with learning disabilities may be inequitable/of poorer quality than healthcare for the general population. This has led to the development of policies and guidance aimed at reducing inequalities and improving health and diabetes care for this population. In terms of diabetes care, specific guidance on reasonable adjustments to services has been produced. However, despite the wealth of discussion around improving quality care for people with learning disabilities, there has been little consideration of how meanings of quality care - and quality diabetes care particularly - are constructed in relation to this population. My thesis aims to investigate the ways in which key stakeholders construct quality diabetes primary care by examining the discursive resources that stakeholders draw on, the ways they position themselves and others in relation to quality care. Within this my thesis further aims to explore how speakers situate responsibility for quality care. An additional aim of this research is to highlight any similarities and differences in the ways in which different stakeholders construct meanings of quality in terms of primary diabetes care. The functions of the discursive devices drawn on and their possible implications for the quality of diabetes primary care for people with learning disabilities will also be considered.

Chapter 2 Literature Review

2.1 Introduction

This chapter reviews the literature which informed this thesis and highlights gaps in the current research which my research questions aim to investigate.
This thesis is built upon the literature on i) learning disabilities and health/diabetes care; ii) quality diabetes care which has focused on the general population; and iii) the more limited literature focusing on quality diabetes care specifically for adults with learning disabilities. This chapter therefore covers literature from the learning disability field and health/diabetes care research. In order to understand the themes and gaps in the existing research, literature was reviewed that has taken a variety of epistemological and methodological approaches. In doing so, a case will be made for furthering our understanding of quality diabetes primary care appointments for adults with learning disabilities from a social constructionist perspective. The chapter is organised according to two key headings:

- The experience of diabetes care appointments for people with learning disabilities
- Quality diabetes care for people with learning disabilities

2.1.1 Literature review strategy

The literature review began with the development of a search strategy; key search terms and their variations were identified that were relevant to the broad topic of diabetes care and learning disabilities. Further relevant search terms were identified relating to more specific topic areas as the review progressed, including terms focused on the topics of learning disability and primary care and quality diabetes care. The search terms were then entered into the Open University library’s search facility, which enables advanced searches of multiple publications organised through databases, subject matter or journal collections. Sources incorporated in the search included social care, psychology and nursing related journals, and the Web of Science database. Variations on key terms and their possible combinations were entered making use of Boolean search operators to manage and refine the search.

Examples of search terms and variations included:

- ‘learning disability’ OR ‘learning difficulty’ OR ‘intellectual disability’ AND ‘diabetes’
- ‘learning disability’ AND ‘appointment’ OR ‘primary care’ OR ‘healthcare professional’ OR ‘practitioner’ OR ‘GP’ OR ‘general practitioner’ OR ‘nurse’
- ‘Social construction’ OR ‘discourse analysis’ AND ‘quality’ AND ‘health care’ OR ‘quality care’
- Diabetes AND ‘patient’ AND ‘experience’ AND ‘primary care’

To keep track of the search a record was kept of the terms used and their results (e.g. number of hits) in a Word table. Since the literature on the specific topic of diabetes care for people with
learning disabilities was limited, no maximum date was included in searches of this literature but for other topics (e.g. broader healthcare and people with learning disabilities) a date limit of 20 years was applied.

Search results were screened according to inclusion and exclusion criteria. Inclusion criteria were that the research was peer-reviewed, written in English, reported primary research and included findings or methodology of relevance to the thesis topic. Articles were excluded where participants had specific learning difficulties such as dyslexia, publications summarised existing research but did not describe new knowledge or did not include content of relevance to the aims of the literature review. Additional website searches were made of learning disability and diabetes charities and NHS and government sites to discover relevant diabetes/learning disability related advice, reports, policy documents and guidance. Literature was also identified by following up citations in papers found through the database searches. In order to manage the literature review and support critical evaluation of the literature a further Word table was produced. This table included columns which recorded each publication’s reference/where it was accessed and summarised: the aims of the study, methodology employed, participants, key findings and conclusions and any further research recommended by the authors. The table was further used to record developing thoughts on the relevance of the existing evidence to my thesis topic and remaining gaps in the literature. To evaluate the existing evidence, the strengths and limitations of each publication were considered, including assessing the transparency and trustworthiness of findings and claims (Shaw, 2010). The initial literature review was conducted at the beginning of the study but was updated regularly throughout the project to ensure that the review remained up to date.

2.2 Diabetes care appointments

Healthcare policy in the UK and internationally is for diabetes patients to self-manage their condition working in partnership with healthcare professionals (Colagiuri, Brown, & Dain, 2011; Department of Health, 2001a, 2008; Diabetes UK, 2019c; Roberts, 2007). Healthcare professionals play an important role in supporting effective management of all types of diabetes. Although the amount of time spent with healthcare professionals may be only a few hours a year, these encounters impact on the day-to-day diabetes care by the person with diabetes (Smallwood, 2009). Support from healthcare professionals should include: working with patients to set goals and develop care plans, providing information and advice on diabetes management, reviewing diabetes management and screening for secondary complications, referring patients to
local diabetes education programmes, helping patients to understand blood test and other screening results, discussing medication options and providing emotional support to build confidence in managing diabetes (Diabetes UK, 2016c, 2016e). Diabetes care usually takes place primarily in primary care with referrals to secondary care where necessary (Care Quality Commission, 2016; Diabetes.co.uk, 2016b). The healthcare professionals that a diabetes patient sees, where consultations take place and the frequency of appointments varies according to type of diabetes, individual needs and local arrangements but all diabetes patients are expected to attend an annual diabetes care review, which usually involves separate appointments with multiple healthcare professionals, such as a GP, diabetes specialist nurse, dietician, ophthalmologist and podiatrist (Diabetes.co.uk, 2016a; Diabetes UK, 2016c). One purpose of these appointments is to review management of the condition, including blood tests to screen long-term blood glucose control by measuring HbA1c2 levels. Good control of glucose levels (within recommended targets) reduces the risk of developing secondary complications of diabetes (Diabetes.co.uk, 2016c; Diabetes UK, 2016h). Other health measures which impact on or are influenced by diabetes are also taken, for example, blood pressure, weight and cholesterol levels (Diabetes.co.uk, 2016a; Diabetes UK, 2016h). A further important purpose of diabetes care reviews is to screen for signs of secondary complications of the condition, including eye screening for signs of diabetic retinopathy, foot care in case of poor circulation/loss of feeling and monitoring of kidney and cardiovascular function (Diabetes UK, 2016c). These checks are crucial because diabetes complications can have serious consequences such as loss of vision, renal failure and amputation, and can lead to premature death, but spotting early signs can often enable effective treatment (Diabetes UK, 2016h; Taggart et al., 2014).

Multiple factors have been found to influence attendance of diabetes care appointments amongst the general population including: gender, ethnicity, mental health, socioeconomic status, perception of the value and effectiveness of attendance, and provision of reminders and clear information by healthcare services (Alam, Speed, & Beaver, 2012; Dyer, Lloyd, Lancashire, Bain, & Barnett, 1998; Elders, Keen, & Gold, 2014; Hardy, O’Brien, & Furlong, 1997; Hynes et al., 2014; Spikmans et al., 2003). Diabetes patients are advised to take an active part in their appointments with healthcare professionals, including keeping records of progress to take to the appointment, writing down points to raise beforehand, asking questions, active listening and making notes during the appointment (Diabetes.co.uk, 2016a; Diabetes.org.uk, 2016; Diabetes UK, 2016c). Numerous factors influence the active engagement of patients during diabetes care appointments, including: patient characteristics such as communication skills, age, ethnicity, education level, mental health, coping style, attachment style, duration of diabetes and health

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2 A measurement of glycated haemoglobin which gives clinicians a picture of the patient’s average blood sugars over the previous 8-12 weeks.
literacy levels (Arora, Neeraj, & Collen, 2000; Cegala, 2011; Cegala, McClure, Marinelli, & Post, 2000; Cooper-Patrick et al., 1999; Haidet, Kroll, & Sharf, 2006; Ishikawa & Yano, 2011; Johnson, Roter, Powe, & Cooper, 2004; McCann & Weinman, 1996; Parker et al., 2012). For example, active engagement has been associated with patients who are women and patients with higher levels of health literacy, whereas lack of engagement in consultations has been associated with male patients, low levels of patient health literacy and patients with clinical levels of anxiety and depression or passive coping styles (Arora et al., 2000; Ishikawa & Yano, 2011). Active engagement in appointments is also facilitated or inhibited by factors relating to healthcare services and healthcare professionals such as appointment length, wait time and practitioner communication style and use of language (Cegala, 2011; Moran, Bekker, & Latchford, 2008; Zandbelt, Smets, Oort, Godfried, & de Haes, 2007). For example, active engagement is facilitated by healthcare professionals taking a patient-centred approach (Cegala, 2011).

2.3 The experience of diabetes care appointments

According to NHS England, one requirement of quality care is that care provided should ‘as far as possible’ provide a positive experience for patients (NHS England, 2016). Approximately 95% of diabetes care takes place outside of healthcare settings and is informed by a relatively small amount of time spent in clinical encounters (once or twice a year). This makes the quality of the experience of these encounters particularly important. In this section I will outline and critique the existing literature that contributes to our limited current understanding of the experience of diabetes care appointments for adults with learning disabilities. To date, research in this area has focused on exploring some aspects of the quality of diabetes care for adults with learning disabilities and the broader experience of diabetes management for this population. I will discuss what this literature reveals about the experience of diabetes care appointments from the perspective of adults with learning disabilities, their supporters and healthcare professionals. For comparative purposes I will briefly consider the literature on the experience for people with diabetes who do not have learning disabilities. I will also consider the limitations of this existing literature and highlight the important gaps in our understanding of this topic that my project aims to explore.
2.3.1 The experience of diabetes care appointments for people without learning disabilities

Existing knowledge on the experience of diabetes care appointments comes primarily from studies focusing on the perspectives of populations who do not have learning disabilities. These studies have reported both positive and negative experiences of consultations with diabetes care practitioners. People reporting positive experiences have described: good encounters with practice diabetes lead nurses; good communication with healthcare professionals; emotional support and availability of healthcare professionals during times of difficulty; and continuity of care (Hinder & Greenhalgh, 2012b; Lawton, Ahmad, Hanna, Douglas, & Hallowell, 2006; Lowes et al., 2015). Negative experiences described include: lack of respect; support or understanding from professionals; patronising, accusatory, judgemental and stigmatising approach/language; enhanced feelings of anxiety, frustration and failure about diabetes management; poor communication from professionals; difficulty accessing professionals and services; and failure of professionals to recognise the individual’s knowledge of their condition and self-management efforts (Dickinson, 2018; Hinder & Greenhalgh, 2012b; Lawton et al., 2006; Li, Drury, & Taylor, 2014; Lowes et al., 2015). The language used by healthcare professionals can also have a profound impact on the experience of living with diabetes (Cooper et al., 2018; NHS England, 2018). Negative experiences sometimes lead people to disengage from services (Care Quality Commission, 2016).

In 2016 the Care Quality Commission conducted a review which aimed to improve understanding of the experience of diabetes care in community services across England, including how well services deliver high quality care (Care Quality Commission, 2016). The review reported positive feedback from people with diabetes about the support from their GP practice to manage their diabetes. Most people reported that they received the checks recommended by the National Institute for Clinical Excellence (NICE), were able to discuss care with healthcare professionals and received good explanations. However, most people also lacked awareness and understanding of their test results, and few had a care plan. The review also highlighted a need for greater emotional support from healthcare professionals and/or referral to specialist psychological services and emphasised the importance of person-centred coordinated care including involvement in decision-making. Absence of person-centred care was equated with lack of compassion and consultations appearing to be tick box exercises.

People with diabetes in the general population have therefore reported mixed experiences of diabetes care services including primary care, expressing a preference for well-co-ordinated
consistent person-centred care that is respectful of their diabetes knowledge and experience. A need for increased attention to emotional wellbeing has also been highlighted in the literature.

A smaller body of literature has explored the diabetes care experience of specific populations including older people, ethnic minorities, children and adolescents, people with disabilities and mental health conditions. Experiences reported in relation to specific populations include: poor understanding of the difficulties or context within which their diabetes management takes place; lack of consideration for emotional impact on carers; poor communication and integration of services between social and medical care; and an absence of adapted information (Calamaro, Saylor, & Hanna, 2018; Li et al., 2014; Lowes et al., 2015; Pera, 2011). The experience of other stakeholders such as carers in relation to diabetes care for people without learning disabilities has also been explored. For example, professionals and staff working in care homes for older people have reported poor communication and integration of services between social and medical care (Fox, Gillespie, Kilvert, & Sinclair, 2013). The existing literature therefore indicates that diabetes care services often do not meet the needs of specific groups who are at higher risk of diabetes and who may experience difficulties managing the condition.

2.3.2 The experience of diabetes care appointments for people with learning disabilities

Although there are currently no papers which specifically focus on the experience of diabetes related primary care appointments from the perspective of people with learning disabilities, their carers or healthcare professionals, a number of case studies, reports and qualitative studies on the overall experience of living with diabetes and supporting diabetes management for people with mild-to-moderate learning disabilities do provide some valuable insights.

The Learning Disabilities Health Observatory point out that people with learning disabilities may feel fearful during diabetes related appointments due to previous negative experiences with healthcare professionals (Turner, 2014; Turner & Emerson, 2013). There is some evidence to suggest that adults with learning disabilities experience diabetes care appointments as frightening and stressful. In qualitative studies of the experience of diabetes in the Netherlands and the UK people with mild-to-moderate learning disabilities and type 1 or type 2 diabetes described struggling with a fear or phobia of needles (Cardol, Rijken, & van Schrojenstein Lantman-de Valk, 2012b; Rouse, 2014). The CQC report of community diabetes care in England describes the example of a woman with learning disabilities who became anxious and distressed recalling the shock she experienced when first told she had to use an insulin pen and being given insufficient time to arrange support for the appointment during which she was trained to use the pen: ‘they
just dumped the insulin on me, that was bad care…’ (Care Quality Commission, 2016: P 11). In New Zealand, a qualitative study consisting of interviews with 14 adults with mild-to-moderate learning disabilities and type 1 or type 2 diabetes reported that some participants found visits to the Diabetes Centre stressful. For example, one participant stated ‘I feel very pressured’ when doctors comment that they have gained weight (Hale et al., 2011: P 227). The authors also report the concerning finding that one participant now refuses to attend the Diabetes Centre ‘...because I was sick of it, got annoying’ (Hale et al., 2011: P 227).

People with learning disabilities who receive diabetes care visits from healthcare professionals in their own home, have reported that they experience this as frustrating and inconvenient since it imposes physical and social restrictions (Hale, Trip, Whitehead, & Conder, 2011; Napthine, 2001). One participant in the New Zealand study reported that they disliked having to wait for the district nurse to come and supervise insulin administration since the nurse often arrived at inconvenient times: ‘my home is out and about; when I stayed home...I was waiting and got bored’ (Hale et al. 2011: P 227). This difficulty was also highlighted in a case study describing the implementation of a new system of supervised self-administration of insulin for one woman with learning disabilities and type 2 diabetes (Napthine, 2001). The woman lived in a residential care environment in the UK and the district nurse had previously visited the home to administer insulin injections and test blood glucose levels twice a day. This arrangement had become inappropriate and the visit by the district nurse was a difficult experience for a number of reasons. These included: the times at which the district nurse visited were not always convenient for the individual and limited her social life (she had to stay in and wait and could not go out for a meal); although she was underweight and staff usually encouraged her to eat they had to discourage her from eating until she had been given insulin; the individual was sometimes asleep when insulin was administered or tired and refused food by the time insulin had been administered. Perhaps unsurprisingly, these difficulties were triggering aggressive behaviour, creating difficulties for care home staff and risk of injury to the district nurse. The author argues that this case study highlights a service deficit probably experienced by other people with learning disabilities who lack choice over their receipt of services ‘and have no alternative but to use these services’ (Napthine, 2001: P 22).

Adults with learning disabilities have reported a number of difficulties communicating with healthcare professionals during diabetes care appointments, including feeling unable to ask questions of healthcare professionals ‘I wouldn’t dare’ (Cardol et al. 2012b: P 356), finding healthcare professionals difficult, dismissive and frustrating and having their preferences (e.g. for injections sites) ignored (Cardol et al., 2012b; Rouse & Finlay, 2016; Rouse, 2014). Co-production
comments from people with learning disabilities informing the NHS *RightCare Pathway* on diabetes for this population reported that people with learning disabilities preferred their support worker or parent to speak to the doctor on their behalf (Kachika, 2017). According to a study by Cardol et al. (2012b) their participants with mild or moderate learning disabilities perceived appointments as professional led check-ups rather than an interaction in which they could participate, ‘hardly ever asked questions’ (Cardol et al., 2012b: P 356), and did not appear to directly communicate with healthcare professionals at all. This is at odds with the current policy recommendations of diabetes patients working in partnership with professionals and taking an active role in their appointments (Department of Health, 2001a; Diabetes.co.uk, 2016b; Diabetes UK, 2016c). A further indication of poor communication during diabetes care appointments is the finding that some people with learning disabilities lack understanding of their diabetes care (Dysch, Chung, & Fox, 2012; Hale et al., 2011), for example not knowing what the blood tests they had were for and expressing confusion over whether their diabetes will be permanent: ‘I’m not sure if I’m going to have it for the rest of my life’ (Dysch et al., 2012: P 42). Furthermore, a study of adults with mild-to-moderate learning disabilities in Yorkshire found low knowledge of the need for foot, eye and dental care, which may suggest a lack of regular explanation of the need and reason for self-care during diabetes reviews (Bryant et al., 2017).

In addition to the difficulty with verbal communication, the existing research suggests that the experience of diabetes care appointments for people with learning disabilities often does not include receiving appropriate information about their condition, medication and self-management (Cardol et al., 2012b; Flood & Henman, 2015; Hale et al., 2011; Maine, 2017). People with learning disabilities have reported that they do not have any written information about diabetes that they can understand (Cardol et al., 2012b); that they do not remember being given any information about diabetes at the time of diagnosis; and that they would like more (and more accessible) information about diabetes (Hale et al., 2011). Healthcare professionals have reported that they are not aware of accessible information on diabetes management or its complications for patients with learning disabilities (Brown et al., 2017). Case studies have also reported that people with learning disabilities do not always receive adequate or appropriate information about safely managing, storing and administering diabetes medication from their pharmacists or healthcare professionals (Care Quality Commission, 2016; Flood & Henman, 2015). A study exploring experience of the self-management of type 2 diabetes by adults with learning disabilities reported that participants with learning disabilities described a lack of information from healthcare professionals which they sometimes blamed for outcomes such as poor glucose control (Maine, 2017). Participants with learning disabilities have also described themselves as having better knowledge of their condition than their healthcare professionals (Maine, 2017).
Furthermore, it is emerging that healthcare professionals may be making clinical judgements to deviate from standard treatment targets for patients with learning disabilities, for example aiming for higher than usually recommended blood sugar levels for fear that the patient cannot manage hypoglycaemia, without explaining the risk of long-term complications associated with this course of action (Brown et al., 2017).

Phillips (2009) points out that the experience of diabetes care appointments for all diabetes patients should include the development of a health action plan centred around the needs of the individual and support to achieve agreed actions (Department of Health, 2002). There is some evidence that health action plans related to diabetes management for people with learning disabilities are not always produced or successfully implemented (Care Quality Commission, 2016). However, Phillips (2009) describes a case where a health action plan was successfully developed to reduce the risk of diabetes for a patient with Down’s Syndrome.

Some authors, including those who have worked with people with learning disabilities and diabetes, have argued that there is a lack of understanding and respect for people with learning disabilities amongst healthcare professionals, which may lead to a poor experience of diabetes care appointments (Flood & Henman, 2015; Kelly, 2011; Napthine, 2001; Rey-conde & Lennox, 2007). Rey-Conde and Lennox (2007) from the Queensland Centre for Intellectual and Developmental Disability report that people with learning disabilities complain that healthcare professionals raise their voices, do not explain procedures, treat them as ‘stupid’ and do not listen to their opinion or give them time to reply to questions (Rey-conde & Lennox, 2007). Some people with learning disabilities have reported being treated with insensitivity during their consultations or at their GP practice reception, for example, not being spoken to directly or not being listened to (Care Quality Commission, 2016).

In discussing some of the difficulties of implementing a new system to empower a woman with learning disabilities in a residential care environment to self-inject insulin, Napthine (2001) provides some insight into the attitudes that people with learning disabilities may experience in their encounters with healthcare professionals. The author, who is a Community Learning Disability Nurse Specialist, describes the most difficult barrier she faced being the expectations of healthcare professionals about what could be achieved by an individual with learning disabilities. Professionals often struggled to recognise that the individual with learning disabilities could and should be involved with their own diabetes management. Despite the clear difficulties and risks inherent in the existing system as described above, the author reports that some professionals lacked understanding of the individual’s needs in relation to their learning disabilities and writes that some professionals ‘were irritated’ and appeared to view the author as ‘being difficult’ when
she explained the problems with the existing system of care for the individual, care home staff and the district nurse (Napthine, 2001: P 21).

Positive experiences of diabetes care appointments and contact with healthcare professionals have been reported. Hale et al. (2011: P 227) found that some participants described positive visits to the Diabetes Centre. For example, one participant reported that his visit ‘had enabled a range of management options to be explored … assisted in his learning how to better manage his diabetes and maintain his independence.’ A case-finding study in the UK involving participants with mild-to-moderate learning disabilities and type 2 diabetes controlled without insulin, found that 73% of their participants reported no difficulty attending appointments for their diabetes and that the majority of participants were able to access diabetes care in general practice (Bryant et al., 2017). Maine et al. (2017) found adults with type 2 diabetes and learning disabilities reported some positive experiences with healthcare professionals and valued positive feedback and encouragement from diabetes nurses (Maine, 2017): ‘It’s quite a boost to my system, when they (diabetes nurse) give me positive feedback, from something that I’ve done.’ (Maine et al., 2017, p. 81). Healthcare professionals have also reported that it is important to empower people with learning disabilities to self-manage their diabetes and have worked together with learning disability professionals to do so (Brown et al., 2017; Turner & Emerson, 2013).

The CQC (2016) review of community diabetes care included some findings specific to people with learning disabilities. Examples of good practice were given including adapted information and education and multiple professionals and agencies working together to give personalised support, such as a food worker visiting daily to support shopping and meal preparation until a newly diagnosed man with type 2 diabetes became confident enough to manage his new diet. However, the review also reported that structured education was rarely offered to people with learning disabilities and that it was unclear whether their education needs had been met in other ways. Some people with learning disabilities said they had been offered access to a course but turned it down because they were unable to arrange support or did not feel it suited their needs (Care Quality Commission, 2016).

Further findings relevant to the experience of diabetes care services include reports that several people with learning disabilities were reluctant to attend health checks, especially those which are more intrusive such as eye screening. An example was also given of extreme exercise and eating behaviour due to concern about levels before the diabetes review. The authors point out that care staff who can support people to safely undertake all checks are important (Care Quality Commission, 2016).
In common with people with diabetes in the general population, people with learning disabilities report mixed experiences of diabetes services. Specific barriers relating to the needs of this population have also been highlighted. The limited existing research suggests that for this population, the experience of diabetes care services including primary care can be motivating, encouraging and person-centred but can also be difficult, stressful and anxiety-provoking. Research on the wider experience of diabetes care therefore gives some insight into the views and experiences of this population on the quality of diabetes primary care services, revealing some concerning experiences. This thesis will aim to further our knowledge of this topic by eliciting views and experiences of quality diabetes primary care from the perspective of people with learning disabilities.

2.3.3 The experience of diabetes care appointments for healthcare professionals

The existing literature refers to multiple healthcare professionals who are involved in the diabetes care of adults with learning disabilities including: GPs, diabetes nurse specialists, district nurses, learning disability nurses, ophthalmologists and podiatrists. Although case studies have provided the perspective of learning disability nurses who support patients with learning disabilities (Napthine, 2001; Phillips, 2009) to date only one study appears to have begun to explore the experience of diabetes care professionals. Focusing on a range of healthcare professionals involved in care for adults with learning disabilities and type 2 diabetes based in a single health service area in Scotland, Brown et al. (2017) explored the perceptions and experiences of learning disability and diabetes care professionals, including one primary care professional. Healthcare professionals who had been involved in service provision for people with learning disabilities reported that they had limited knowledge and understanding of the specific needs of patients with learning disabilities and described challenges relating to: communication, capacity to consent to treatment, difficulty accessing accessible information, inconsistencies relating to family/paid carers of people with learning disabilities, time and resources required to make reasonable adjustments and lack of networks with other professionals involved in the care of the individual (Brown et al., 2017).

Despite the limited existing research into the experience of healthcare professionals supporting people with learning disabilities and diabetes, the broader research into diabetes care for this population does highlight some challenges that healthcare professionals may face. Healthcare professionals may often be unaware that a patient has learning disabilities and so are unable to
make reasonable adjustments to services. For instance, the audit of retinal screening services in Bradford, found that in over 40% of cases the information that the patient had learning disabilities was not recorded in the patient demographics held by the retinal screening service (Pilling, 2014a, 2014b).

Healthcare professionals may lack training, knowledge and experience of the challenges people with learning disabilities face when managing diabetes (Flood & Henman, 2015; Kelly, 2011; Napthine, 2001). Understanding the needs of people with learning disabilities can be difficult since these will vary greatly from people with mild disabilities who need occasional support to people with severe or profound learning disabilities who receive full time care (Flood & Henman, 2015; Mencap, 2015; Phillips, 2009; Rey-conde & Lennox, 2007). In relation to primary care services for people with diabetes and learning disabilities, House et al. (2018) point out that practice nurses may have limited experience of this population preventing them from developing the necessary expertise (House et al., 2018). Flood and Henman (2015) point out that some people with mild-to-moderate learning disabilities mask support needs with an appearance of self-sufficiency and a tendency to agree with professionals even if they have not understood what has been said. In the case of pharmacists, if a paid or family carer tends to pick up prescriptions the pharmacist may have very little interaction with the individuals themselves and so may be unaware of their needs or how to spot that support may be necessary (Flood & Henman, 2015). The differing support needs of people with learning disabilities mean that healthcare professionals may need to liaise with paid and family carers, community learning disability teams and social services to varying extents. It has been argued that healthcare professionals have a role in educating and supporting paid and family carers who may share some responsibility for diabetes management (Taggart, Truesdale-Kennedy, & Scott, 2015; Turner, 2014).

Research indicating a lack of understanding about diabetes amongst people with learning disabilities, the reported reluctance of these individuals to ask questions during appointments, and descriptions of problematic or difficult attitudes from healthcare professionals suggests that professionals may experience difficulties communicating with people with learning disabilities (Cardol et al., 2012b; Hale et al., 2011; Rey-conde & Lennox, 2007). Qualitative studies have reported that both people with learning disabilities and their carers emphasise the importance of support from a carer during diabetes care appointments (Cardol et al., 2012b; Cardol, Rijken, & van Schrojenstein Lantman-de Valk, 2012a; Hale et al., 2011; Rouse & Finlay, 2016). Research taking a social constructionist approach has reported that autonomy in terms of the daily management of diabetes is negotiated between people with learning disabilities and their paid or family carers (Rouse & Finlay, 2016; Whitehead, Trip, Hale, & Conder, 2016). Conversation
analytic studies of diabetes consultations for adolescents with type 1 diabetes suggest that when a third person (parent/guardian) is present, the healthcare professional must negotiate challenges relating to autonomy (Buchbinder, 2009a; Silverman, 1987b). Whether similar difficulties are experienced in relation to diabetes care appointments for adults with learning disabilities has not so far been explored.

Other challenges for healthcare professionals highlighted in the existing literature include: recognising the difference between typical behaviour and signs of distress; providing accessible information about self-management of diabetes; acknowledging that features of some specific conditions can impede diagnosis and treatment of secondary complications of diabetes; understanding the issue of capacity to consent to treatment and the need to allow additional appointment time (Brown, Duff, Boyd, & Shaw, 2012; Chee & Olczak, 2008; Napthine, 2001; Pilling, 2014a, 2014b).

For healthcare professionals, effectively supporting people with learning disabilities to manage diabetes is therefore likely to be complex. Although there is currently little research giving the perspective of healthcare professionals on the experience of diabetes care appointments for this population, research outside of the diabetes literature suggests that healthcare professionals experience difficulties in consultations with people with learning disabilities generally, including: communication barriers, lack of continuity of care, conflicts of interest with carers and lack of experience or training in relation to learning disabilities and associated health problems or needs (Lennox, Diggins, & Ugoni, 1997; Lennox, Van Driel, & van Dooren, 2015; Melville et al., 2005). A recent online survey of UK GPs found that over half reported that communication issues were an obstacle to meeting the needs of people with learning disabilities and autism, 98% said that they wanted more training on meeting the needs of this population and 25% reported that they did not have time to make reasonable adjustments (Dimensions, 2019). It seems likely that healthcare professionals experience similar challenges during diabetes care appointments with people with learning disabilities. However, their voice is largely missing from the literature.

2.3.4 The experience of diabetes care appointments for carers

Guidance on diabetes care for this population, and research including qualitative studies focusing on the perspective of adults with learning disabilities and diabetes, have emphasised that paid and family carers play an important role in supporting all aspects of diabetes care including
People with mild-to-moderate learning disabilities living in community housing, supported living and with family have reported that family or paid carers help them to prepare for appointments and that they appreciate carers going with them to diabetes care appointments to prompt them if they become tongue tied during the appointment, ask questions, provide moral support and explain information afterwards (Cardol et al., 2012b; Care Quality Commission, 2016; Kachika, 2017; Rouse & Finlay, 2016). As described above, healthcare professionals have been advised to work with carers to support effective communication with patients with learning disabilities when delivering diabetes services (Kachika, 2017; Pilling, 2014b, 2014a; Rey-conde & Lennox, 2007; Turner, 2014; Turner & Emerson, 2013). Paid or family supporters therefore appear to frequently play a very important role in supporting communication between diabetes patients with learning disabilities and healthcare professionals during diabetes care appointments. In fact, Cardol et al. (2012b) conclude that their participants did not seem to communicate with healthcare professionals directly but were dependent on others to gain information about their condition. Little is currently known about the views of supporters on their roles and responsibilities in relation to diabetes care appointments. However, in terms of the daily tasks of diabetes management, support workers have emphasised the importance of recognising the individual’s rights to autonomous decision-making and have described their own role as encouraging and enabling healthy/safe choices and overseeing but not taking control of diabetes care (Rouse & Finlay, 2016; Whitehead et al., 2016).

Although a number of qualitative studies have focused on the role and experience of the family or paid carer in supporting adults with learning disabilities to manage diabetes generally, few give any clues to the carer’s experience of diabetes care appointments (Cardol et al., 2012a; Rouse & Finlay, 2016; Trip, Conder, Hale, & Whitehead, 2015). In the Netherlands and the UK, paid carers have reported that diabetes care appointments are an important aspect of the support that they provide, that they offer support and prompts during appointments and explain information afterwards (Cardol et al., 2012a; Rouse & Finlay, 2016). Family carers taking part in a co-production initiative for the NHS Diabetes Pathway commented on the usefulness of being able to contact a doctor or nurse when necessary and the value of appointments conducted in a community/home setting (Kachika, 2017). A study conducted in New Zealand examined the role of 17 key workers supporting self-management of diabetes for adults with learning disabilities in residential or independent living services (Trip et al., 2015). The authors mention that key workers were responsible for facilitating access to primary healthcare and that all participants supported individuals with learning disabilities to attend their GP for either 3 monthly or an
annual check. However, further details of this role or their experiences of interacting with healthcare professionals are not given.

There is little information available on carers’ experiences of liaising with healthcare professionals. Case studies have suggested that carers are concerned about accountability, confused over the boundaries between their roles and responsibilities and those of healthcare professionals, and experience frustration over a lack of cooperation when attempting to access specialist services (Napthine, 2001; Turner & Emerson, 2013).

Although it has been argued that healthcare professionals should support and inform the carers of people with learning disabilities and diabetes, whether carers are well informed about diabetes care and feel supported by professionals is unclear. For example, support staff and care managers in residential environments in New Zealand and the UK have been found to lack knowledge of the existence of a diabetes care plan or of who the healthcare professionals involved in managing the individual’s diabetes are and when the next appointment is due (Hale et al., 2011; Shah et al., 2006). Family carers and staff in supported living environments in Australia have also reported feeling concerned that they do not know enough about diabetes yet are responsible for taking the person they support to their diabetes care appointments (Rey-conde, Lennox, & McPhee, 2005). Diabetes and learning disability professionals report that although family members and support workers play a crucial role in supporting people with learning disabilities both to access diabetes services and to manage the condition, they lack knowledge and understanding of diabetes (Brown et al., 2017). They also report that inconsistencies in care by paid and family carers can lead to confusion and poor diabetes management (Brown et al., 2017). On the other hand, in community houses and residential facilities for people with learning disabilities in the Netherlands, some staff reported being able to access healthcare professionals regarding diabetes management if they needed to (Cardol et al., 2012a).

Therefore, the existing literature on the experience of diabetes care for people with learning disabilities indicates that key stakeholders may face challenges in relation to diabetes care appointments. These include difficulties accessing and experiencing effective appointments, providing support and providing accessible and effective diabetes care services. Paid and informal/family supporters often play a key role in ensuring people with learning disabilities can access appointments. There is limited research that specifically reflects on the experience of diabetes care appointments for this population and a particular lack of research focusing on the experience of primary care services.
2.4 Quality diabetes care for people with learning disabilities

Evidence that people with learning disabilities experience inequalities in healthcare has led to the establishment of national policies and programmes to monitor and improve the quality of healthcare including diabetes services for this population (Association of Directors of Adult Social Services et al., 2015; Mencap, 2012; NHS Digital, 2018b; NHS England, 2015). This section investigates the ways in which the concept of quality care has been defined and researched in the literature, with a focus on research into quality diabetes care for people with learning disabilities. Findings contributing to our knowledge of quality diabetes care for people with learning disabilities will also be examined. An argument will be made for the value of research taking a social constructionist approach to this topic, attending to the role of discourse in constructing the meaning of quality care in relation to diabetes care for people with learning disabilities.

2.4.1 Defining ‘quality care’

There are numerous definitions of quality healthcare including diabetes care in the existing literature on quality care. These definitions vary according to whether they emphasise: completion of care processes, accessibility and effectiveness, clinical quality or patient and/or professional experience, structures and/or outcomes, individual users of healthcare or populations, technical quality, provider skill, equality or efficiency, sustainability and cost (Ahmed, Burt, & Roland, 2014; Campbell, Roland, & Buetow, 2000; Care Quality Commission, 2016; McGlynn, 1997). It has also been argued that in relation to diabetes care in particular, quality care supports successful self-management (Care Quality Commission, 2016; Pera, 2011).

According to NHS England and the Department of Health, in order to be considered high quality, care must be: clinically effective (from both patient and clinician perspective), safe and (as far as possible) provide a positive experience for patients (Darzi, 2018; Llanwarne, Newbould, Burt, Campbell, & Roland, 2017; NHS England, 2016; West & West, 2008). Similar definitions have been employed to describe and assess quality care for people with learning disabilities but often with a particular emphasis on consideration of equality, accessibility and the upholding of legal rights (Kachika, 2017; Miranville, 2019; Turner, 2014).

Quality in diabetes care has been described as a multi-dimensional concept (Ahmed et al., 2014) and there does not appear to be an agreed and consistent definition of ‘quality’ across the literature. Nevertheless, numerous organisations have set out recognised quality standards and
guidelines for diabetes care which aim to ‘improve effectiveness, safety and experience of care’ (Jabbour & Stephens, 2015) and to work towards ‘making diabetes care safe, effective, patient-centred, timely, efficient and equitable’ (Diabetes UK, 2016f). Diabetes care quality guidelines include the 15 healthcare essentials developed by Diabetes UK, which detail 15 checks, tests and services that all diabetes patients should receive from their healthcare team as described above (Diabetes UK, 2016a). Similarly, the National Institute for Clinical Excellence describes nine key care processes that diabetes patients should receive (Jabbour & Stephens, 2015). Research often measures and assesses the quality of diabetes care against such quality standards (Diabetes UK, 2016d; Edge, Swift, Anderson, & Turner, 2005; Grant, 2010; Grant, Haq, & Barnes, 2012; Gray, Millett, O’Sullivan, Omar, & Majeed, 2006; Health and Social Care Information Centre, 2011, 2016c, 2016b; Mc Hugh et al., 2011; McInnes, 2012). Here, quality is defined by the organisations that set out care quality standards such as NICE and Diabetes UK and whether these standards have been achieved is largely assessed by the researcher, based on healthcare records and/or ratings from patients and/or clinicians. From this point of view good diabetes care meets quality standards such as measurement of BMI and HbA1c levels and supports the achievement of recommended treatment targets for these measurements.

In common with the wider diabetes care literature described above, researchers have examined data on some diabetes care quality indicators for people with learning disabilities and compared this information with care quality targets such as those published by NICE, the National Service Framework and Diabetes UK (Diabetes UK, 2016a; Lacey, 2014; NHS Commissioning Board, 2012). They have also made comparisons with available data on the same or similar measures in the wider non-learning disabled population (Anwar et al., 1998; Balogh et al., 2015; Glover & Evison, 2012; Pilling, 2014a, 2014b; Public Health England, 2016b; Rohrer et al., 2010; Shah et al., 2006; Shireman, Reichard, Nazir, Backes, & Greiner, 2010; Taggart, Coates, & Truesdale-Kennedy, 2012). Significantly lower rates of monitoring and/or poorer results, for example, of HbA1c levels in patients with learning disabilities than in the wider population and/or recommended target levels are interpreted as signalling poor quality or inequitable care. Comparable screening rates and results for people with and without learning disabilities and/or in line with recommended targets are believed to demonstrate good quality or equitable diabetes care.

Research into the quality of diabetes care in the wider population has also explored the views and experiences of patients and clinicians on the quality of diabetes services by asking patients to report or rate their experiences through questionnaire surveys or using qualitative methods including semi-structured interviews and focus groups (Ahmed et al., 2014; Balf et al., 2013; Edwall, Hellström, Öhrn, & Danielson, 2008; Lawton et al., 2006; Lawton, Peel, Parry, Araoz, &
Douglas, 2005; Stenner, Courtenay, & Carey, 2011). Here, quality is explored from the perspective of the diabetes patient and/or healthcare professionals. A good quality diabetes care appointment in relation to experience is much more broadly defined, ranging from specific options made available in questionnaires to more participant-led descriptions in qualitative interviews. Although, as described in section 2.3, while this research examines the experience of living with diabetes and gives some insight into diabetes care for this population, there is currently little published research which focuses on exploring the quality of diabetes care from the perspective of patients with learning disabilities, those who support their diabetes management or healthcare professionals. This is an important limitation since research with the wider population suggests that stakeholders may assess the quality of their consultations in ways which cannot be captured in records of care processes (Balfe et al., 2013; Lawton et al., 2006).

My thesis aims to address this knowledge gap by using qualitative methodology to explore quality care in relation to diabetes primary care appointments from the perspective of key stakeholders.

Although research has not directly explored what constitutes a quality diabetes care appointment for patients with learning disabilities, in addition to the successful completion of care processes, the recommendations for improvements and adjustments to diabetes care appointments for this population appear to be based on the assumption that a quality appointment is one in which:

- people with learning disabilities and their carers receive information in a form that they can understand
- steps are taken to minimise fear, stress, frustration and inconvenience
- there is good respectful communication between all stakeholders
- people with learning disabilities actively participate in the consultation and ask questions
- people with learning disabilities are supported to learn about diabetes, improve their management and have some level of involvement and autonomy
- people with learning disabilities and their carers feel supported, informed and confident in their knowledge of diabetes and how to manage it.

(Cardol et al., 2012b; Dysch et al., 2012; Hale et al., 2011; Napthine, 2001; Pilling, 2014a; Rey-conde & Lennox, 2007; Turner, 2014; Turner & Emerson, 2013).

2.4.2 Quality of diabetes care for adults with learning disabilities

As described in section 2.2, numerous reports and studies have concluded that people with learning disabilities experience inequalities in healthcare, receiving poor care in comparison to the general population including: difficulty accessing healthcare services, preventable emergency
hospital admissions, delayed diagnosis, a lack of reasonable adjustments to services, increased risk of early deaths and preventable deaths (Emerson et al., 2011; Glover & Evison, 2012; Heslop et al., 2013; Heslop, Lauer, & Hoghton, 2015; Mencap, 2012; Michael, 2008; Parliamentary and Health Service Ombudsman and Local Government Ombudsman, 2009). Research specifically exploring the quality of diabetes care for adults with learning disabilities is currently very limited but the majority of existing survey and audit studies indicate that quality of diabetes care may be poor and that people with learning disabilities are less likely to receive diabetes care reviews and screenings for secondary complications than diabetes patients who do not have learning disabilities (Balogh et al., 2015; Glover & Evison, 2012; Pilling, 2014b; Shah et al., 2006; Shireman et al., 2010; Taggart et al., 2012).

The Learning Disabilities Health Observatory examined hospital admission records in England over a four year period and found that although diabetes is an ambulatory care sensitive condition (usually treated effectively in primary care) people with learning disabilities are more likely to experience emergency hospital admission for complications of diabetes than people without learning disabilities (Glover & Evison, 2012). Similarly, a study of diabetes primary care in Canada found that people with learning and developmental disabilities were 2.6 times more likely to be hospitalised for diabetes related ambulatory care sensitive conditions than those without (Balogh et al., 2015). The authors argue that these findings reflect weaknesses in the primary care system’s provision of diabetes care for adults with learning disabilities (Glover & Evison, 2012; Turner & Emerson, 2013).

A further indicator of inequity in the quality of diabetes care for adults with learning disabilities comes from survey studies and service audits in Northern Ireland and specific areas of England and the United States. These studies have revealed that people with learning disabilities in their samples attended fewer diabetes review appointments and screening appointments than diabetes patients without learning disabilities and that screening levels for complications of diabetes for this population do not meet national quality standards for diabetes care (Pilling, 2014b; Shah et al., 2006; Shireman et al., 2010; Taggart et al., 2012).

Shireman et al. (2010) examined the quality of diabetes care for adults with developmental disabilities (including learning disabilities) in one US state (Kansas) who were enrolled in the

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3 The Improving Health and Lives Learning Disabilities Health Observatory (now part of Public Health England) was set up by the Department of Health to provide information about the health of people with learning disabilities in England following a recommendation by the Independent Inquiry into access to healthcare for people with learning disabilities (Michael, 2008).
Medicaid programme\(^4\). Over a 12 month period the study looked at outcome measures that indicate quality of diabetes care, including: evidence of glucose testing (HbA1c), eye exams, lipid testing (e.g. cholesterol) and primary care visits. The study found that adults with developmental disabilities were screened for quality indicators of diabetes care less frequently than overall screening rates for the programme. For example, only 51.7\% of people with developmental disabilities had received an HbA1c or glucose test compared to 77\% overall and 29\% of people with developmental disabilities had received eye examinations compared to 55\% overall. The authors conclude that their results suggest lower rates of quality of diabetes care measures for people with developmental disabilities than national rates and that this is likely to lead to higher rates of hospitalisation and lower quality of life for people with developmental disabilities and diabetes (Shireman et al., 2010).

A survey study exploring the quality of diabetes care for adults with learning disabilities in Northern Ireland over a 12 month period concluded that diabetes was often poorly controlled (Taggart et al., 2012). The sample of this study included people with type 1 and type 2 diabetes and mild, moderate and profound learning disabilities. More than half of the sample (58\%) had a reported HbA1c level over recommended target levels. Other areas of concern were that more than half of their sample was overweight, 17\% were morbidly obese and 10\% had attended emergency departments for a diabetes related condition such as hypo or hyperglycaemia. Additionally, national standards for good diabetes management relating to monitoring of diabetes and screening for complications set out by NICE guidelines (NICE, 2015a), the National Service Framework for Diabetes (Department of Health, 2001a, 2008; Roberts, 2007) and Diabetes UK (Diabetes UK, 2012) were only partially met (Taggart et al., 2012). For instance, only 59\% of their sample had received HbA1c testing in the past 12 months. Data is not given on quality of care indicators for the wider population of diabetes patients in Northern Ireland, but the authors conclude that their results indicate that people with learning disabilities are not receiving complete monitoring of their diabetes and experience inequalities in their diabetes care. Their results also suggested that receipt of some recommended monitoring was associated with the severity of learning disability, for example, HbA1c checks were less frequent for those with mild learning disabilities (49.4\%) than for those with moderate (65\%) or profound (72\%) disabilities. Intriguingly, both Shireman et al. (2010) and Taggart et al. (2012) report that lack of comprehensive diabetes monitoring is disappointing since the majority of their samples had been in contact with a primary care provider during the period studied. Whether or not this contact was related to their diabetes is not reported but as with the findings on diabetes related

\(^4\) A social healthcare programme for people on low income.
emergency hospital admissions for people with learning disabilities this perhaps implies a failing in primary care services.

Two small scale studies examining quality of diabetes care for adults with learning disabilities in specific areas of England also suggest inequalities in receipt of diabetes care related appointments and reviews (Pilling, 2014a, 2014b; Shah et al., 2006). A recent audit of retinal screening in Bradford found that national standards for screening for diabetic retinopathy were not met for eligible patients known to have learning disabilities (Pilling, 2014a, 2014b). Levels of successful screening (for which there is a recorded outcome) for people with learning disabilities were at 65% compared to 81% at a national level and the 80% standard set by NICE (Lacey, 2014). More encouragingly, a survey of diabetes care in care homes in the East Elmbridge and Mid Surrey Primary Care Trust did report that 100% of residents with diabetes and learning disabilities living in Trust care homes had received an annual review including blood pressure monitoring, blood test and review of medication plans (Shah et al., 2006). However, the study also found limited availability of an annual review by an optometrist (12%) or podiatrist (17%) for residents with diabetes living in care homes for people with learning disabilities.

A case-study finding conducted in three districts of West Yorkshire with people with mild-to-moderate learning disabilities and type 2 diabetes controlled without insulin found that although glycaemic management was similar to that of the general population with type 2 diabetes, one fifth of their participants had higher than recommended HbA1c levels and the majority were overweight or obese (Bryant et al., 2017; House et al., 2018).

Three studies have given a more positive picture of the quality of diabetes management and monitoring for patients with learning disabilities. Preliminary findings from the Learning Disability Health Observatory’s study of records from 36% of general practices in England found no significant difference between numbers of diabetes patients with and without learning disabilities who had up-to-date and satisfactory HbA1c scores (Glover, 2016; Public Health England, 2016b). Focusing on people with type 1 diabetes and Down’s Syndrome, a survey study in Scotland and an examination of data from a diabetes centre in Germany found evidence that type 1 diabetes showed similar or better glycaemic control in people with Down’s Syndrome than in the general population (Anwar et al., 1998; Rohrer et al., 2010). The authors of these studies do not attribute good glycaemic control to good healthcare but to the stable lifestyle of their samples who lived largely in institutional settings (Anwar et al., 1998; Rohrer et al., 2010).
Reports from the England and Wales National Diabetes Audit have made comparisons to the care received by all people with diabetes and give a mixed picture regarding the quality and equality of diabetes care for adults with learning disabilities (NHS Digital, 2017, 2018b). The audit recorded receipt of eight of the nine annual checks described in the NICE recommended care processes (the eye screening care process was not included in the data) and reported that people with learning disabilities and type 1 diabetes were more likely to receive these eight care processes annually than patients without learning disabilities whereas people with learning disabilities who have type 2/other diabetes were less likely to receive these annual checks (NHS Digital, 2018b). In particular, people with learning disabilities who have type 2 diabetes were not receiving urine albumin checks to check for early stages of kidney disease. NICE recommends treatment targets for HbA1c, blood pressure and serum cholesterol to reduce the risk of complications and the audit found that people with learning disabilities and type 1 and type 2 diabetes are more likely to achieve each of these treatment targets. The audit also reports that people with learning disabilities are as likely to be offered structured education as people without learning disabilities but information on attendance levels was unavailable (NHS Digital, 2018c). Rates of care processes and treatment targets achieved for people with learning disabilities have remained stable since 2015 when data became available about this population (NHS Digital, 2018c, 2018b).

Although the existing survey and audit studies do suggest inequalities in the diabetes care that people with learning disabilities receive, a limitation of the existing literature is that the findings are restricted to the type of information available to audits or the responses of the individual completing the surveys. People with learning disabilities living in care homes or supported living may be supported by more than one member of staff and may also be supported by friends and family. The surveys reported by Taggart et al. (2012) and Shah et al. (2006) were completed by one member of staff (a key worker, learning disability nurse or care manager) and Taggart et al. report that their questions on quality indicators were often left incomplete. It is possible that this indicates a problem with paid carers having access to information on the diabetes care appointments and their outcomes rather than that a review/appointment has not taken place. Equally the audits only give available information that has been recorded on the Diabetic Eye Screening Programme electronic database, in general practice records or appointments for which people claimed Medicaid (Bryant et al., 2017; Pilling, 2014a, 2014b; Public Health England, 2016b; Shireman et al., 2010). For example, Bryant et al (2017) point out that their participants were drawn from general practice registers which mainly record those with more significant disability and that the information on test results returned by GPs was often incomplete (Bryant et al., 2017). Furthermore, this data can only indicate the quality of care for those attending
appointments and receiving care processes. The results of these quantitative studies are therefore open to interpretation.

A further limitation of the audits and surveys described above is that whilst they often highlight problems with the quality of diabetes services for people with learning disabilities, they rarely provide any explanation for these deficiencies beyond the authors’ speculation. Equally, where studies suggest good care and similar levels of monitoring for diabetes patients with and without learning disabilities (Anwar et al., 1998; Public Health England, 2016b; Rohrer et al., 2010) there is no information on how this has been achieved. One exception is Pilling (2015a; 2015b) who does report reasons given for lack of retinal screening on the Diabetic Eye Screening Programme’s electronic database. These included: failure to attend appointments, patient being labelled ‘unsuitable’ by the GP, unsuccessful attempts at screening and failure to be offered an appointment. There is no further information on why patients failed to attend, criteria used by GPs to decide that a patient is ‘unsuitable’ or what contributed to the success or failure of screening appointments. However, the author also reports on a focus group consisting of carers, the retinal screening programme director, a vision charity representative and a member of the local community health facilitation team who suggested reasonable adjustments to improve rates of retinal screening in response to the findings of the audit (Pilling, 2014a, 2014b).

Although the findings of these audits, surveys and reviews have often been used to question the quality of diabetes care services for people with learning disabilities to date, there is limited understanding of the quality of diabetes care from the perspective of healthcare professionals, carers or people with diabetes and learning disabilities themselves. Examination of how key stakeholders constitute quality care in relation to diabetes appointments may help to explain the reasons behind the inequalities identified in the data and suggest ways these might be remedied.

2.4.3 Barriers and reasonable adjustments to diabetes care services for people with learning disabilities

It is a legal requirement for health services to make anticipatory ‘reasonable adjustments’ to ensure equality of access to their services under the Equality Act 2010 and the NHS and Social Care Act 2008 so that these services are as accessible and effective for people with disabilities as for those without (Department of Health, 2010; Hatton et al., 2011; Turner, 2014; Turner & Emerson, 2013). Recommendations for improving the quality of healthcare for people with learning disabilities regularly advise healthcare professionals to ensure that making reasonable adjustments to healthcare services is standard practice (NHS Improvement, 2018; Northway &
Dix, 2019). A further way of exploring quality of diabetes care services is to consider whether they are ‘accessible and effective’ for people with learning disabilities (Turner, 2014).

Reasonable adjustments to diabetes services for people with learning disabilities can reduce complications of diabetes, diabetes related A&E attendance, GP visits and missed appointments in this population (Kachika, 2017). Nevertheless, research, reviews and guidance documents describe and propose many barriers that would suggest failure on the part of diabetes care services to make reasonable adjustments to enable equal access and effective consultations for people with learning disabilities. Barriers include: communication, behavioural and cognitive difficulties, inconsistent/inadequate care provision, lack of local services, poor communication between different services and professionals who lack training in and understanding of the needs of people with learning disabilities (Brown et al., 2012, 2017; Kelly, 2011; Pilling, 2014a; Reichard, Stolzle, Sella, & Shireman, 2012; Rey-conde et al., 2005; Taggart et al., 2012; Turner, 2014).

To date, research has not focused on reasonable adjustments and their contribution to the quality of diabetes care services from the perspective of key stakeholders. There are, however, a number of sources which provide examples of good practice and adjustments to diabetes care programmes, services and education for people with learning disabilities (Brown et al., 2012; Care Quality Commission, 2016; Kelly, 2011; McAuley & Hicks, 2013; Napthine, 2001; Pilling, 2014a, 2014b; Taggart, Truesdale-Kennedy, et al., 2015; Turner & Emerson, 2013). Additionally, a number of authors have recommended facilitators to diabetes care appointments for people with learning disabilities in response to findings of inequality of care, or based on their clinical experience (Pilling, 2014b; Rey-conde & Lennox, 2007; Taggart et al., 2012; Turner, 2014). More recently the NHS RightCare Pathway has published guidance on reasonable adjustments aimed at commissioners and providers of diabetes services who work with people with learning disabilities and diabetes (Kachika, 2017). The recommended and described reasonable adjustments have aimed to: improve accessibility and effectiveness of diabetes care services and to make diabetes resources and education programmes accessible.

### 2.4.3.1 Accessing services

A major barrier to reasonable adjustments highlighted by existing research is that diabetes care services may be unaware that a patient has learning disabilities, for example, if this information is not passed on to screening services by general practices (Pilling, 2014a, 2014b). It has therefore been recommended that the presence of a learning disability should be highlighted to diabetes care services so any necessary adjustments can be made to make screenings accessible (Pilling, 2014b, 2014a; Taggart et al., 2012). Where responsibility lies for ensuring this information is
passed on is unclear. Some research has suggested that there is a ‘hidden majority’ of adults particularly with mild/moderate learning disabilities who identify as having learning disabilities but are not known to health and/or specialist support services (Emerson & Glover, 2012; Hatton, 2015). When considering healthcare generally for this population, Emerson and Glover point out that the lack of accurate information held by health services makes it difficult for practices to make reasonable adjustments that take into account the needs of people with mild/moderate learning disabilities. The Learning Disabilities Health Observatory’s report on reasonable adjustments to diabetes services for people with learning disabilities describes a retinal screening service in Teignbridge and Torbay which worked with the local Learning Disability Team, Disability Equality Action Group and primary care liaison nurses to improve access to diabetic retinopathy screening for people with learning disabilities (Turner & Emerson, 2013). Adjustments to services included: identifying people with learning disabilities eligible for screening so that they could receive easy read information, delaying automatic referral to the hospital following one unsuccessful screening so that a second attempt could be made and developing an easy read screening invitation letter and a booklet describing the process of retinal screening.

Other reasonable adjustments focus on enabling effective encounters with diabetes services for example, by improving communication or reducing the stress and anxiety that many people with learning disabilities experience due to an unfamiliar environment or a previous negative experience of healthcare professionals (Turner, 2014). Turner recommends addressing fear of healthcare professionals through desensitisation and working with local specialist learning disability services (Turner, 2014). For example, Pilling (2014a: P 201) describes a case study in which attending two separate appointments following advice from the individual’s brother familiarised the patient with the environment and led to cooperation and successful photographing of the eye during the second visit though on his first visit he ‘was reluctant to put his chin on the machine for the photograph and would only sit on the chair beside it.’ Similarly at the retinal screening service in Teignbridge and Torbay, primary care liaison nurses worked to identify patients with learning disabilities who may require desensitisation to ensure successful screening (Turner & Emerson, 2013). A type 2 diabetes education, monitoring and screening programme in Enfield familiarises people with learning disabilities with testing equipment and explains the process before blood is taken (McAuley & Hicks, 2013).
2.4.3.2 Information and education

There are a growing number of resources which aim to provide accessible information on diabetes for people with learning disabilities using a variety of media. For example, in Northern Ireland a booklet about type 2 diabetes was co-produced by a local health facilitator working with people with developmental disabilities and their carers (Scott, 2013; Speakup Self Advocacy, 2010; Taggart, Truesdale-Kennedy, et al., 2015). Similarly, the ‘OK Diabetes’ project at the University of Leeds has produced a guide to type 2 diabetes for Diabetes UK aimed at people with learning disabilities (Diabetes UK, 2014a). There are also accessible films about diabetes available online and the University of Queensland has produced a website aimed at people with learning disabilities and their carers (Queensland Centre for Intellectual and Developmental Disability, 2009; Speakup Self Advocacy, 2010; Taggart, Coates, et al., 2015). A number of these publications describe the need for diabetes care appointments such as annual reviews and eye and foot examinations, and explain that people with diabetes should speak to healthcare professionals such as doctors, nurses and dieticians (Diabetes UK, 2014a; Queensland Centre for Intellectual and Developmental Disability, 2009; Scott, 2013). Some accessible resources describing the procedures involved in screening appointments, including retinopathy, going for a blood test and foot care have also been developed (Derbyshire County PCT, 2013b, 2013a; Hampshire Partnership NHS Trust, 2011; Public Health England; NHS, 2018; See Ability, 2011b, 2011a). The limited evaluations of these resources suggest that people with learning disabilities and their carers find them useful (Lennox, Edie, Taylor, Rey-Conde, & McPhee, 2009).

Research into diabetes care for people with learning disabilities has often focused on the development of education programmes to prevent or manage diabetes (Ali, Stone, Peters, Davies, & Khunti, 2006; Dunkley, Tyrer, Spong, et al., 2017; Taggart, Coates, et al., 2015b). Although participation in diabetes self-management education is recommended by health services internationally and has been found to be beneficial to the self-management of diabetes in the general population, some studies indicate that people with learning disabilities are less likely to be offered the opportunity to take part in these programmes and that available programmes are not designed at a level appropriate to the needs of this population (Brown et al., 2017; Care Quality Commission, 2016). Structured education programmes for people with type 2 diabetes have been adapted or specifically developed to make information on diabetes care, including information on attending appointments, accessible to people with learning disabilities (Kelly, 2011; McAuley & Hicks, 2013; Taggart et al., 2017; Taggart et al., 2015). Self-advocacy groups have also developed user-led diabetes training (Opening Doors, 2016; ourvoiceoursay2, 2019). Theory based
adaptations of existing programmes which have been assessed through feasibility trials include: STOP Diabetes, OK Diabetes and DESMOND-ID (Bryant et al., 2017; Dunkley, Tyrer, Gray, et al., 2017; Taggart et al., 2017). A review of education programmes for type 2 diabetes adapted for adults with intellectual and developmental disabilities reports adaptations including: breaking aims and objectives into understandable and achievable chunks; use of easy read and pictures/symbols, inclusion of carers and exploration of barriers and solutions to making lifestyle changes (Taggart et al., 2018). Assessments have found evidence of improvement to diabetes management such as improved HbA1c levels and increased levels of physical activity (Bryant et al., 2017; Dunkley, Tyrer, Spong, et al., 2017; Taggart et al., 2017, 2018).

Therefore, research into the quality of diabetes care for people with learning disabilities has so far defined quality care according to the successful completion of care processes and achievement of quality standards (Pilling, 2014a; Shireman et al., 2010; Taggart et al., 2012). Additionally, policy documents and reports relating to healthcare for people with learning disabilities emphasise the need for reasonable adjustments to be put in place to ensure that services are equally ‘accessible and effective’ for this population (Hatton et al., 2011; Kachika, 2017; Turner & Emerson, 2013). However, it is not known whether people with learning disabilities, their carers or healthcare professionals define quality diabetes care appointments with reference to the completion of care processes, accessibility and effectiveness and/or other understandings of quality care. This project aims to explore what constitutes a quality diabetes care appointment for all stakeholders.

2.4.4 Responsibility and quality care

As described above, multiple barriers to quality diabetes services for people with learning disabilities have been identified, including lack of clarity over responsibility for diabetes care for people with learning disabilities (Pilling, 2014b; Taggart et al., 2012; Trip et al., 2015). Taggart et al. (2012) argue that inequalities in diabetes care experienced by this population may centre on the question of responsibility. The question of where responsibility for ensuring quality diabetes care for people with learning disabilities is situated has not so far been explored.

Policy documents and guidelines on diabetes care for this population position healthcare services, including commissioners and general practice staff, as responsible for making reasonable adjustments to ensure equal accessibility and quality of health and diabetes care for people with learning disabilities and often emphasise the role of primary care trusts and healthcare professionals (Diabetes UK, 2018; Kachika, 2017). The roles and responsibilities of primary care
for the health of people with learning disabilities has been emphasised by reviews and inquiries (Michael, 2008; Miranville, 2019). This responsibility grew with the shift in care from hospital to community settings (Michael, 2008). Research indicates that general practice was slow to adapt, with primary care staff expressing confusion over the extent of their responsibility for the healthcare of people with learning disabilities and the role of specialist services (Disability Rights Commission of England and Wales, 2006; Powrie, 2003; Webb & Stanton, 2009b). Brady and Bollard (2009) argue that confusion over the roles and responsibilities of specialist learning disability services and primary healthcare may have prevented practices from becoming able to identify and meet the needs of people with learning disabilities (Brady & Bollard, 2009). The responsibilities of supporters, particularly paid support workers in social care to ensure health needs are met have also been highlighted (Department of Health, 2001b).

2.4.5 Quality care as a socially constructed concept

The multiple and varied coexisting definitions of quality of diabetes care indicate that quality care may be a fluid concept influenced by social and cultural structures (Aldousari, 2015; Campbell et al., 2000; Edwards, Staniszew ska, & Crichton, 2004; Pope, van Roye, & Baker, 2002; Walshe, Nagington, & Luker, 2013). Thus, one approach to studying quality in diabetes care that may be a particularly enlightening is social constructionism. Research taking a social constructionist approach to investigating quality healthcare has argued that the roles of stakeholders in care are produced and constrained by socially available discursive resources (Nagington, Luker, & Walshe, 2013b). Therefore, quality healthcare cannot be captured and measured through quantitative data alone but should take an approach that provides reflective spaces and address the notion of quality by considering the individual as dialectically constructed and constructing subjects (Leget, 2015; Nagington, Luker, & Walshe, 2013a).

A limited number of studies exploring the social construction of quality of care have demonstrated that multiple and sometimes conflicting versions of quality of care are constructed drawing on culturally available resources (Aldousari, 2015; Nagington, Walshe, & Luker, 2016; Walshe et al., 2013). For example, good quality care may be described as having short waiting times, good public image or the provision of culturally appropriate services (Aldousari, 2015). The authors argue that the ways in which quality of care is constituted has implications for improving quality of care, how patients utilise services and how stakeholders evaluate quality of care (Aldousari, 2015; Walshe et al., 2013). In a study of palliative care despite reporting
postponement of routine tasks and feeling reluctant to ask for additional care, patients and carers did not evaluate the nursing care as poor since they drew on ideas of the ‘busyness’ of nurses who would in theory ‘do anything’ to construct quality palliative nursing care (Walshe et al., 2013). Busyness was a common discourse which restricted the way patients conceptualised and accessed psychosocial care, medications and physical care. It prevented patients from re-imagining or asking for more care (because nurses are too busy) and sometimes made current physical care unviable (‘we’ll tell someone to do it tomorrow’). The authors concluded that any nursing action can be made unviable and busyness is a way in which patient and carer subjectivities become unquestioningly restricted (Nagington et al., 2016; Walshe et al., 2013).

Prevailing discourses of good healthcare change over time and context, for example quality care has variously centred on compassion/economy and patient/customer (Leget, 2015; Mol, 2008).

It is possible that the ways in which stakeholders construct quality diabetes care appointments for people with learning disabilities has implications for the type of care received and that understanding these constructions may help to explain and challenge the proposed inequalities experienced by this population. Despite a wealth of research taking a positivist approach to the study of quality of health/diabetes care (Ahmed et al., 2014; Burt et al., 2014; Campbell et al., 2000; Kontopantelis, Reeves, Valderas, Campbell, & Doran, 2013; Sofaer & Firminger, 2004), there is currently only limited research on the social construction of quality of healthcare within the general population (Aldousari, 2015; Walshe et al., 2013) and there does not appear to be any published research exploring this topic for people with learning disabilities. In light of research findings which question the quality of primary care for diabetes patients with learning disabilities (Balogh et al., 2015; Glover & Evison, 2012; Shireman et al., 2010; Taggart et al., 2012) and current UK policies to monitor and improve quality of healthcare for people with learning disabilities (Association of Directors of Adult Social Services et al., 2015) exploration of how quality is constituted by key stakeholders in relation to diabetes care appointments is particularly worthy of exploration. My thesis will begin to address this knowledge gap by exploring the social construction of quality diabetes care appointments for adults with learning disabilities by diabetes patients with mild-to-moderate learning disabilities, those who support their diabetes management and healthcare professionals.

2.5 Conclusion

This chapter has set out the contextual background for my thesis, examined what is currently known about the experience of diabetes care appointments for adults with learning disabilities
and the existing research on the quality of the diabetes care that this population receives. Despite the increased prevalence of diabetes amongst people with learning disabilities and indications that diabetes patients with learning disabilities attend fewer diabetes care appointments than diabetes patients without learning disabilities, there remain many gaps in our understanding of the experience of diabetes care appointments for people with learning disabilities. In particular, perspectives of diabetes patients with learning disabilities, their supporters and healthcare professionals on the quality of their diabetes care appointments have not been the focus of research. Nevertheless, qualitative research on the wider experience of diabetes care for this population suggests that appointments can be experienced as difficult and frustrating for all stakeholders.

Research into quality in healthcare has identified multiple socially available definitions of quality care, informed by social and cultural structures. These influence how the concept of ‘quality care’ is constructed and assessed by stakeholders and the roles that stakeholders can play. The limited literature on the social construction of quality health care indicates that examining the topic from a social constructionist perspective reveals dominant discourses on quality care and positionings of key stakeholders which produce and maintain power relations and inequalities within healthcare. Despite the numerous calls for and commitments to improving quality care for people with learning disabilities, there is currently no research that investigates how the meaning of quality care for this population is constituted. Furthermore, where responsibility for the quality of healthcare and particularly diabetes care of people with learning disabilities is situated may be key to improving quality of care and reducing inequalities. The concept of responsibility for diabetes management for the general population has been found to be variously positioned with different stakeholders in the existing literature. However, research has not so far focused on how the concept of responsibility for quality diabetes care for people with learning disabilities is constructed.

In order to begin to further our understanding of these knowledge gaps, my project aimed to investigate the social construction of quality care and responsibility for quality care in relation to diabetes primary care appointments for adults with mild-to-moderate learning disabilities from the perspective of key stakeholders.
2.6 Research Aims and Questions

As described above, a particular gap in current knowledge of diabetes care appointments for adults with learning disabilities is that the meanings of quality and responsibility for quality diabetes care appointments for this population constituted by key stakeholders have not been explored. This thesis aims to enhance understanding of these topics through elicitation of the experience of diabetes care appointments within primary care for adults with learning disabilities, those who support them and healthcare professionals.

These aims break down into the following research questions:

1. How do adults with mild-to-moderate learning disabilities and diabetes, those who support their diabetes management and healthcare professionals discursively construct quality diabetes care appointments during accounts of the experience of diabetes care appointments?

2. What similarities and differences are there in the ways in which different stakeholders discursively construct quality diabetes care appointments for adults with mild-to-moderate learning disabilities?

3. How do adults with mild-to-moderate learning disabilities and diabetes, those who support their diabetes management and healthcare professionals discursively construct responsibility for the provision of quality diabetes care for adults with learning disabilities during accounts of the experience of diabetes care appointments?

Chapter 3 Methodology

3.1 Introduction

In my PhD research I have made use of qualitative methodology informed by patient and public involvement initiatives to elicit accounts of the experience of diabetes primary care appointments for adults with learning disabilities from key stakeholders. Taking a social constructionist perspective, I then explored the discursive construction of the concepts of quality care and responsibility for quality care in relation to diabetes primary care appointments within these accounts. This chapter outlines the rationale for my chosen methodology and describes my
methodological procedures including recruitment, data collection and data analysis. Steps taken to ensure quality and rigor will then be described. The chapter ends with a reflection on some of the methodological challenges that arose during data collection and how these were managed.

3.2 Theoretical Framework

This research was informed by a critical discursive psychological approach (Edley, 2001; Wetherell, 1998), underpinned by a social constructionist theoretical framework. A key assumption of the social constructionist perspective is that it is not possible to access ‘real’ and pre-existing views, facts and perceptions since reality does not exist separately from the categories and concepts we use to understand and represent the world (Burr, 2015; Sullivan, 2010). From this approach our taken for granted knowledge and common ways of understanding the world are actively created through social interactions (Burr, 2015; Gergen, 1985; Sullivan, 2010). Research taking this perspective therefore explores how our shared understandings of the world are constructed in interaction, such as through the use of language to make sense of, describe and construct the world and, within this, how these constructions are used to perform social actions such as making claims, building identities or defending a position (Burr, 2015; Sullivan, 2010). This research took a critical discursive psychological perspective, which explores: how people build accounts of events and construct the world through language, the performative functions of language, the historically and culturally situated nature of talk and how dominant accounts may produce, sustain and resist power ideologies within society (Burr, 2015; Edley, 2001; Potter, 1996; Potter & Wetherell, 1987; Taylor, 2001b). A discursive approach has successfully informed previous research with people with learning disabilities and their supporters (Finlay & Lyons, 2000b; Jingree, 2015; Jingree & Finlay, 2008, 2011, 2012; Rouse & Finlay, 2016; Scior, 2003; Wilcox, Finlay, & Edmonds, 2006) and research into diabetes care (Boman, Borup, Povlsen, & Dahlborg-Lyckhage, 2012).

In line with the theoretical assumption that meaning is socially created, my research questions ask how the concepts of quality and responsibility were discursively constructed by stakeholders during accounts of diabetes care appointments for people with learning disabilities, since gaining an understanding of participants’ ‘real’ views and perceptions would not be considered possible from this epistemological standpoint. In turn, these assumptions impact on the method of data collection. In contrast to the wealth of existing research on quality of diabetes care, this research did not use questionnaires or structured interviews to assess the quality of diabetes care according to researcher or professional developed criteria, since a social constructionist
epistemology assumes that it is not possible to access a stable and measurable perception or truth. Furthermore, it has been argued that a qualitative approach which does not make use of researcher defined criteria may be particularly appropriate to research the complex concept of quality care (Aldousari, 2015; Pope et al., 2002) and to elicit experiences of diabetes care (Ingadottir & Halldorsdottir, 2008). I have therefore made use of semi-structured interviews to elicit accounts of the experience of diabetes primary care appointments and explored these accounts to identify the ways in which language was used to construct concepts of quality care.

Consistent with social constructionist assumptions, data analysis and interpretation of the findings have not involved searching for a stable and generalisable definition of quality or responsibility within accounts but have instead applied a critical discourse analysis to discover the ways in which multiple versions of quality were socially constructed, and the social actions this performed.

Social constructionism and critical discursive psychology assume that our constructions of the world are a product of the culture and period of time in which they are created and can produce and sustain power relations since different constructions exclude some social actions and legitimate others (Burr, 2015; Edley, 2001; Gergen, 1985; Wetherell, 1998). For example, constructions of people with learning disabilities as incompetent and subject to risky behaviour by more powerful groups such as psychologists and support workers may exclude subject positions of autonomy for this population and make legitimate the control of their daily lives by more competent and powerful others. In my interpretations of my findings I have therefore also considered the discursive resources available within the context of current discourses around people with learning disabilities, discourses of healthcare for people with learning disabilities and diabetes care generally. Furthermore, I have considered the potential impact of the construction and management of discourses identified on diabetes care for people with learning disabilities, including the implications of dominant discourses used by stakeholders and possible power relations they may produce, reproduce or challenge. Taking a social constructionist perspective to the topic allows an examination of how culturally available resources are managed in the production and reproduction of inequalities in diabetes care provision for people with learning disabilities, which can then be challenged.

3.2.1 Critical Discourse Analysis

Interview transcripts were analysed using critical discourse analysis (Edley, 2001; Wetherell, 1998). In common with other forms of discourse analysis, critical discourse analysis assumes that
the meaning of concepts such as quality and responsibility are socially constructed through talk in interaction and that the way in which these concepts are constructed performs social action, such as presenting a positive identity (Edley, 2001). Critical discourse analysis also assumes that the culturally dominant ways of representing reality and available subject positions that can be taken up by speakers or attributed to others can empower or disempower social groups, contributing to the wider social operation of power (Edley, 2001; Wetherell, 1998). In addition to identifying socially available discourses, critical discourse analysis therefore aims to understand the implications of these discourses for constructing and reconstructing social inequalities so that they can be challenged (Taylor, 2001b).

Discourse analysis was chosen over other methods of analysis such as thematic or phenomenological analysis following reports in the literature that a social constructionist/discursive approach could be valuable to the investigation of quality care (Aldousari, 2015; Campbell et al., 2000). Critical discourse analysis has been successfully used to analyse the accounts of people with mild-to-moderate learning disabilities (Finlay & Lyons, 2000b; Fullana, Pallisera, & Díaz-Garolera, 2019; Jingree & Finlay, 2011; Rouse & Finlay, 2016; Scior, 2003) and their carers (Jingree, 2015; Jingree & Finlay, 2012; Rouse & Finlay, 2016; Wilcox et al., 2006). The tools of critical discourse analysis have been applied to the talk of healthcare professionals including Diabetes Nurse Specialists in Sweden (Boström & Öresland, 2018; McCreanor & Nairn, 2002). McCreanor and Nairn (2002) argue that language plays a central constitutive role in the social practices of primary healthcare and found the tools of critical discursive psychology valuable in highlighting power relations and the reproduction/reinforcement of healthcare inequalities in the talk of general practitioners (McCreanor & Nairn, 2002).

Discourse analysts have argued that discourse analysis is an underused but particularly revealing and relevant method in learning disability research (Jingree & Finlay, 2008; Nunkoosing & Haydon-Laurelut, 2011; Rapley, 2004; Scior, 2003; Wilcox et al., 2006). In particular, critical discourse analysis is an especially useful and appropriate method of analysis since this approach allows identification and understanding of the operation of power and resistance to power in the lives of people with learning disabilities (Rapley, 2004). Additionally, the assumption that multiple versions of reality are constructed, makes irrelevant questions about the accuracy and reliability of the accounts of people with learning disabilities due to inconsistency that have sometimes been levelled at research with this population (Scior, 2003).
3.3 Study Design

In this section I will explain the rationale for my choice of participants and method of data collection.

3.3.1 Sampling rationale

In order to elicit accounts of the experience of diabetes care appointments from the perspective of key stakeholders, recruitment targeted people with learning disabilities, those who supported their diabetes management and healthcare professionals through purposive sampling. I aimed to recruit a minimum of 5 participants from each stakeholder group so that a minimum total of 15 participants would be recruited. This is consistent with previous qualitative research utilising critical discourse analysis which has found that interviews with between 10-15 participants provides sufficient data to allow the identification of interpretative repertoires and subject positions (Jingree, 2015; Jingree & Finlay, 2011; Rouse & Finlay, 2016; Seymour-Smith, Wetherell, & Phoenix, 2002). A maximum of 10 participants were aimed for from each stakeholder group (30 participants overall) to ensure that data collection and analysis could be completed within the available time, and to account for possible attrition. Recruitment ended when, on agreement with my supervisors, the richness of the interview data was sufficient for analysis and could be completed within the timeframe.

3.3.1.1 People with learning disabilities

The existing literature indicates that people with mild-to-moderate learning disabilities may be a particularly important group to focus on because dilemmas around the balance of autonomy and support received by this population may impact on the quality of their diabetes care (Rouse & Finlay, 2016; Taggart et al., 2012). Adults (aged 18 and over) with mild-to-moderate learning disabilities who had the capacity to consent were recruited to take part in the research. Unlike some previous research on learning disabilities and diabetes (Shireman et al., 2010; Taggart, Truesdale-Kennedy, et al., 2015) this did not include people with developmental
disabilities/disorders who did not also have learning disabilities. Since people with learning
disabilities can have difficulty with memory, to help ensure recall and that participants had some
recent experience of diabetes care appointments within primary care, attendance of a primary
care diabetes appointment within the past three months was part of the initial inclusion criteria.
Due to initial recruitment difficulties the criteria were reviewed and extended to include
participants who had attended appointments within 12 months of the interview.

In common with previous qualitative research on diabetes management for this population
(Cardol et al., 2012b; Hale et al., 2011) recruitment criteria included adults (aged 18 and over)
with mild-to-moderate learning disabilities who used diabetes services in primary care settings,
including those with specific syndromes in which diabetes is prevalent such as Down’s Syndrome,
as well as people with pervasive developmental disorders. Recruitment criteria did not exclude
people from taking part on the basis of age, gender or ethnicity but due to the limited number of
potential participants it was not possible to selectively recruit to ensure diversity. Demographic
details were recorded during recruitment (see section 3.4.1 for full details). Where possible,
length of time since diagnosis of diabetes was recorded but in order to capture diversity of
experiences and to prevent narrowing the pool of participants, there was no minimum length of
time since diagnosis for inclusion in the study.

Like previous qualitative studies exploring the experience of diabetes management for this
population (Cardol et al., 2012b; Dysch et al., 2012; Hale et al., 2011), I aimed to recruit people
with a diagnosis of type 1 and type 2 diabetes. This widened the potential participant pool and
took into account reports by some previous research that people with learning disabilities and
those supporting them are not always aware of the type of diabetes that the person has (Cardol
et al., 2012b). Equal numbers were not aimed for since type 2 diabetes is more prevalent and
people with type 1 diabetes are more likely to be reviewed in specialist clinics than people with
type 2 diabetes.

Existing research on diabetes management for people with learning disabilities has come under
criticism for relying on self-report from the individual with learning disabilities and/or their carer
of a diagnosis of diabetes and the presence and severity of a learning disability (MacRae et al.,
2015). In cases where people with learning disabilities were recruited through learning disability
services, staff used records from these services to verify the presence of a learning disability and a
diagnosis of diabetes. However, as outlined in the literature review, there are believed to be a

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5 ‘Developmental disorders’ covers pervasive developmental disorders such as cerebral palsy and autistic
spectrum conditions which sometimes, but not always include a level of learning disability (World Health
'hidden majority' of adults with learning disabilities who are not in receipt of specialist support services (Emerson & Hatton, 2008; Hatton, 2015). In order to lessen the chances of excluding this group from the study, people who self-identified as having a mild-to-moderate learning disabilities were also recruited even when it was not possible to administratively verify their learning disability and diabetes.

This research focused on people with learning disabilities living in community settings (independently, with family or in supported living environments). People living in residential care environments such as treatment and assessment units were not recruited due to the difficulties of accessing, recruiting, consenting and interviewing people with high support needs living in institutional environments. In section 3.3.4 I outline my recruitment strategy.

As described in the literature review, information on the numbers of people with learning disabilities who also have diabetes is currently scarce (Emerson et al., 2011; Flood & Henman, 2015; McAuley & Hicks, 2013; McVilly et al., 2014; Rey-conde et al., 2005). To date there is no existing data on the number of people with learning disabilities across the UK who also have a diagnosis of type 1 or type 2 diabetes meaning the potential participant pool for this research was unknown.

3.3.1.2 Supporters

The existing literature indicates that people with learning disabilities often receive support during diabetes care appointments from paid or family carers (Cardol et al., 2012b; Napthine, 2001; Phillips, 2009). Participants with learning disabilities were asked to nominate someone who supports them with their diabetes care appointments and this person was also invited to take part in separate interviews on their experience of supporting people with learning disabilities in relation to diabetes care appointments. This ‘support’ not only referred to being present during the individual’s diabetes primary care appointment but could include help given in preparation for appointment attendance as well as putting advice from healthcare professionals into practice after the appointment.

The original design aimed to recruit people with learning disabilities and someone who supports them in a dyad: one person with learning disabilities and one person who supports that individual in relation to their diabetes care appointments such as a paid or family carer. Recruiting people with learning disabilities and a supportive other in pairs has proven effective in previous research exploring the healthcare experiences of people with learning disabilities (Ali et al., 2013; Donner,
Mutter, & Scior, 2010; Rouse & Finlay, 2016). Conducting qualitative interviews with patients and their family or professional carers can aid recruitment of hard to access groups, because the carer’s role of protective gatekeeper shifts to that of participant (Kendall et al., 2009).

Supporters were recruited through nomination by the person they support (six people) or through invitations to participate sent to supported living services and advocacy groups (one person). Supporters were initially only recruited if the individual they supported agreed to take part. Since it is important to gain the perspective of people with learning disabilities, where the individual with learning disabilities consented to take part in the project but either did not have a supporter who wished to take part or did not feel that they received support relating to their diabetes care appointments, the individual with learning disabilities was still recruited. This widened the potential pool of participants with learning disabilities (which is a hard to access group) and aimed to increase the opportunity for recruiting people with learning disabilities from the ‘hidden majority’ who are not in receipt of support from services and are often excluded from research.

3.3.1.3 Healthcare professionals

The perspective of diabetes care practitioners on quality of services of people with learning disabilities has been relatively neglected. Healthcare professionals such as diabetes/practice nurses, GPs and healthcare assistants who have experience of taking part in diabetes primary care appointments with a patient who has mild-to-moderate learning disabilities within the past three months in a primary care setting were invited to take part in separate interviews. This time frame was reviewed during recruitment and adjusted to 12 months due to difficulties recruiting participants within the limitations of the original recruitment criteria. Healthcare professionals were recruited independently of participants with learning disabilities since it was possible that people with learning disabilities may have felt uncomfortable with the idea that I would also be speaking to their healthcare practitioner, preventing them from speaking freely about their experiences. Participants with learning disabilities may have found it particularly difficult to describe negative experiences or views which appear critical of their healthcare professionals if this person was also being interviewed as part of the project. They may also have been concerned that this could impact on their care. Furthermore, limiting recruitment of healthcare professionals to people nominated by the participants with learning disabilities may have caused logistical difficulties (for example, recruiting busy professionals identified by patients has proved difficult in previous research (Kendall et al., 2009)) and would have narrowed the potential pool of participants from this stakeholder group.
3.3.2 Semi-structured Interviews

The study design for this thesis made use of semi-structured interviews. A qualitative methodology was chosen since existing research on the topic has often taken a quantitative approach such as audits and questionnaires, which have limitations in terms of gaining the perspective of stakeholders as described in section 2.4. Alternative methods of qualitative data collection and analysis were considered, including the use of video elicitation interviews (Henry & Fetters, 2012). However, a review of the literature and discussions with a researcher experienced in this approach highlighted challenges of this methodology, particularly in the recruitment of a specific population, suggesting that this route may be impractical within the confines of my PhD thesis.

Qualitative research and semi-structured interviews in particular are an appropriate method for eliciting experience relating to diabetes care because this approach provides the space for participants to share their experiences without being constrained by the researcher or practitioner defined options or definitions often used in questionnaires and surveys (Gomersall, Madill, & Summers, 2011; Ingadottir & Halldorsdottir, 2008). Assessment of quality care is dependent on perspective (user, professional, public, politician). Qualitative interviews are an especially helpfully way of understanding user views of services and why some care is viewed as poor quality (Pope et al., 2002). It has also been argued that it is ethical to account for the views of those at the receiving end of care (Nagington et al., 2013a). Semi-structured interviews are especially useful for participants with learning disabilities because open ended questions help to avoid acquiescence often found in responses to structured interviews and questionnaires by this population (Finlay & Lyons, 2001, 2002). The flexibility of semi-structured interviews also allows the interviewer to adapt questioning style and structure to match the communication skills and context of individual interviewees and to follow up any issues raised by participants. Previous studies have also demonstrated that semi-structured interviews can provide valuable insight into patient experience of diabetes management in the general population (Edwall et al., 2008; Parry, Peel, Douglas, & Lawton, 2006; Peel, Parry, Douglas, & Lawton, 2005) and for people with mild-to-moderate learning disabilities and their supporters (Dysch et al., 2012; Rouse & Finlay, 2016).
3.3.2.1 Visual prompts

Guidance on interviewing people with learning disabilities suggests that comprehension, recall and communication can be supported by the use of visual prompts (Nind, 2008; Prosser & Bromley, 2012; Rodgers, 1999). Researchers who have made use of visual prompts such as pictures and photos during semi-structured interviews report that prompts aid understanding and memory and improve the quality of the narrative (Bunning, 2007; Rodgers, 1999; Scior, 2003). Since some people with learning disabilities have difficulty recalling their experiences, particularly where there is a time lapse between the appointment and the interview, semi-structured interviews were supported by visual aids to prompt memory of the processes which usually take place during a diabetes care appointment. These consisted of A4 laminated printouts including images and a brief written description. Since no single available easy read print document on diabetes included images covering all aspects of the primary care diabetes appointment process, a search was made of diabetes course materials, easy read healthcare documents/images and other documents for appropriate images depicting the 15 healthcare essentials described by Diabetes UK (Diabetes UK, 2012) and other aspects of the appointment process (see appendix 1).

3.3.3 Patient and Public Involvement Initiatives

Patient and public involvement (PPI) describes the active involvement of patients and/or members of the public in the research process as advisors and/or co-researchers (INVOLVE, 2015d; National Institute for Health Research, 2014). PPI is becoming increasingly important in health and social care research and inclusion of a plan for PPI is an expectation of the National Research Ethics Service (INVOLVE, 2015b). Previous studies on diabetes and learning disabilities have found that people with learning disabilities can make a valuable contribution to the research process in an advisory capacity (Cardol et al., 2012b; Dunkley, Clarkson, & Tyrer, 2013). Advantages of PPI include enhanced clarity of study documents and strengthened ethics committee submissions (INVOLVE, 2015a; National Institute for Health Research, 2014; Rouse & Rae, 2016). Asking a patient group to feedback on a study’s findings and conclusions can also provide a check on the validity of findings, give valuable insight into the interpretation, relevance and implications of findings from a patient perspective and provide recommendations for the improvement of health services based on the study’s findings (INVOLVE, 2015a; Larkin, Boden, & Newton, 2015; NIHR, 2014).
In order to ensure that my study documents were clear, accessible and relevant I recruited an advisory group of people with mild-to-moderate learning disabilities and diabetes by approaching self-advocacy groups for adults with learning disabilities to:

- Provide feedback on the design and clarity of study documents (participant information sheets and consent forms)
- Review a summary of my findings/conclusions (providing their response to the findings, what they might mean and ideas for dissemination routes)
- Provide feedback on the clarity of an accessible summary of the findings to be sent to participants with learning disabilities at the end of the project.

Meetings were designed based on the advice provided by INVOLVE (INVOLVE, 2015c). At the request of the University’s Human Research Ethics Committee a proforma and copies of documents and meeting plans were reviewed and approved by the HREC before recruitment of the advisory group. Five people with mild-to-moderate learning disabilities and experience of healthcare appointments relating to chronic health conditions were recruited from one self-advocacy group in the Midlands of England. Two meetings were held, one face-to-face and one remotely (via email). The initial meeting involved getting to know the group, reviewing the study documents and their accessibility to people with learning disabilities, as well as discussion of recruitment. Study documents were revised based on feedback from the initial face-to-face meeting and sent by email to the group for review. The group further reviewed and discussed the amended documents, providing additional feedback and the documents were adjusted in line with the group’s advice (see appendix 2). Initial plans for PPI including further face-to-face meetings were adjusted due to practical considerations.

Key feedback from the advisory group were:

- Reduce & simplify the text
- Include a hard copy contact form & stamp addressed envelope because some people with learning disabilities are uncomfortable with phone and email communication
- Give appointment cards to act as a reminder
- Replace ambiguous images
- Place images to the left of text (in the order that people read).
During the research, positive feedback was received on the accessibility of these documents and the use of visual prompts by supporters and self-advocates who supported recruitment and/or took part in the research (recorded in my research diary and on social media).

3.3.4 Methodological Procedures

3.3.4.1 Recruitment strategies

Participants were recruited through purposive sampling of adults with mild-to-moderate learning disabilities, their supporters and primary care diabetes practitioners. Separate invitation to participate letters/emails, recruitment adverts and information sheets were designed aimed at people with learning disabilities (see appendix 3 & 4) and healthcare professionals (see appendix 7 & 8).

3.3.4.1.1 Recruitment of people with learning disabilities

Routes to recruitment for people with learning disabilities were learning disability services and charitable organisations including advocacy groups. Recruitment via NHS organisations was considered but decided against following consultation with the local R & D. All organisations approached for recruitment were sent a copy of the invitation to participate letter/email, recruitment advert and information sheet for people with learning disabilities (see appendix 3 and 4).

Since people with learning disabilities can be a hard to access group and previous experience suggested focusing on one region would not lead to the recruitment of sufficient participants with learning disabilities and diabetes, recruitment targeted organisations within the South and Midlands of England.

Charitable organisations which support people with diabetes and organisations which support people with learning disabilities and their families, social enterprise and advocacy/self-advocacy groups and healthcare and disability charities were asked to disseminate study details. I also offered to visit organisations to speak about the project. Out of 46 charities approached, 17 agreed to promote the study to members through their websites, social media or newsletters or to discuss the project during advocacy group meetings.
Care providers (charities, private organisations, housing associations and council) who run services such as work experience, day centres and supported living for adults with learning disabilities were contacted via email, letter or social media and asked to circulate details to their staff and people they support (see appendix 5 for recruitment letter/email). Where possible, named people such as operations/communications manager/trustees were targeted. Where this information was unavailable, general information email addresses/enquiry forms were used.

Initial arrangements to disseminate details through the local Learning Disability Partnership were disrupted by staff changes. Online databases of learning disability services in the South East of England which included charity and council run supported living and day centres were therefore searched for relevant service providers who might support people with mild-to-moderate learning disabilities. Managing organisations (e.g. charities and housing societies) and individual home/service managers were contacted. A total of 41 separate supported living environments in the South East of England were contacted, nine directly responded that they had circulated details of the research to people with learning disabilities and/or staff and service managers within their organisation.

3.3.4.1.2 Supporters

Supporters were recruited by asking participants with learning disabilities to identify someone who supported them in relation to their diabetes care appointments. Due to difficulty recruiting the minimum number of participants from this stakeholder group, the recruitment criteria were extended to include paid or family carers who had not directly supported participants with learning disabilities within this study and charities and advocacy groups were asked to pass details of the research including the supporter participant information sheet (see appendix 6) to anyone who had supported at least one individual with learning disabilities in relation to their diabetes primary care appointments.

3.3.4.1.3 Healthcare professionals

Healthcare professionals were recruited from within one East of England Clinical Commissioning Group, as per ethical approvals. Recruitment was supported by Diabetes UK via the Take Part in Research section of their website and social media through the charity’s Research Communications Manager (Diabetes UK, 2016g). This web page promotes diabetes research
looking to recruit both patients and healthcare professionals. I also sought permission to include details of the study in the newsletter of the Diabetes UK *Primary Care Network* and other diabetes, nursing and general practice newsletters and social media (Facebook and Twitter) such as *Nursing Times*.

General practices were approached to promote the project through two routes: direct contact from the researcher, a request from the Clinical Commissioning Group’s Communications and Engagement team. I directly contacted general practices through practice managers and (where information was available) diabetes nurses and GPs with a stated interest in diabetes care working within the CCG. This involved 44 electronic and 92 hardcopy invitations to participate (including invitation to participate letter (see appendix 7), recruitment advert, information sheet (see appendix 8) & Health Research Authority letter of approval. Practices were identified via the NHS Choices website. For each practice, an initial invitation to participate letter/email was sent and a follow up letter or email up to 2 months after the initial invitation. The local CCG circulated project details to the CCG’s Diabetes Programme Manager, targeted diabetes care staff and emailed their list of general practices (150 practices). A notice was placed in the CCG’s electronic GP newsletter. Diabetes training providers and healthcare professional groups were also approached to promote the study via social media.

A project website was developed using WordPress, including a summary of the project, recruitment adverts and participant information sheets for all participant groups [https://diabeteslearningdisabilities.wordpress.com/](https://diabeteslearningdisabilities.wordpress.com/). The site included a contact form which potential participants could use to send enquiries directly to the researcher. A link to the website was included in requests to promote the study sent to all organisations. A Facebook page was also developed for the project and shared via friends/contacts and Twitter was used to promote the research (see appendix 9).

### 3.3.4.2 Recruitment procedure

Recruitment adverts and information sheets invited potential participants to contact the researcher by phone or email for more information or to express an interest in taking part in the research. On the advice of the advisory group, recruitment information for people with learning disabilities included a hardcopy expression of interest form (see appendix 10) because some people with learning disabilities may be uncomfortable with phone or electronic communication. Two people completed the hardcopy form and asked advocates to scan and email the form to
express their interest. Four people with learning disabilities recruited through one self-advocacy group requested contact through Twitter, five people asked a supporter to phone or email the researcher on their behalf. Arrangements were then made to speak to the individual and where requested their supporter by phone, in person or via video link depending on the individual’s preference. Recruitment of some people with learning disabilities included a combination of phone/video and then face-to-face discussion about the research to give people the opportunity of meeting the researcher and receiving information in different formats before deciding whether to take part.

Initial contact with participants from all stakeholder groups included: checking that they fulfilled the recruitment criteria, arranging to send information sheets to those who had not already seen these, explaining the aim of the project, explaining what would be expected of participants and inviting them to ask questions about the research. Potential participants were then given at least 24 hours to consider taking part. Arrangements were made to meet to obtain informed consent and conduct the interview for those who decided to participate. People with learning disabilities who agreed to take part were asked to identify someone who supports them with their diabetes primary care appointments and this person was then approached to take part in a separate interview. Following the advice of the advisory group, participants with learning disabilities were offered an appointment reminder card stating the date, time and location of the interview to be sent by post or email (see appendix 11).

3.3.4.3 Reflections on the recruitment process

Recruitment criteria in terms of time since last appointment was reviewed and adjusted from three to twelve months due to difficulty recruiting sufficient numbers within the three month limit. Additionally, some potential participants with learning disabilities and/or their supporters estimated time since last appointment based on the understanding that their diabetes reviews were usually 6/12 months apart.

One challenge of recruiting people with learning disabilities was that following talks to self-advocacy groups people with learning disabilities were sometimes keen to take part in interviews who did not meet the recruitment criteria. It was therefore necessary to be very clear when discussing the research that I could only interview to people who had a diagnosis of diabetes (not people with an interest in diet or who had been told they might be at risk of developing diabetes).
Whilst ethically justified, the recruitment practice of asking participants with learning disabilities to identify supporters who might take part in the research did not result in the minimum participants from this stakeholder group. Despite reflecting on the involvement of others in their appointments and diabetes care, people with learning disabilities sometimes reported that they did not need or receive support in relation to their diabetes care appointments. Recruitment criteria for supporters were therefore adjusted to allow supporters to take part if the person they supported did not participate.

A further issue with the recruitment of supporters was that sometimes people with learning disabilities volunteered the name of a family or paid supporter who assisted with their appointment attendance but who did not agree to take part. Paid support workers were sometimes reluctant to take part in an interview in their own time but were concerned about participating during work hours that should be spent supporting the individual. In the case of the support worker Lucia, with the agreement of the person she supported, Lucia contributed her perspective during the interview with the person she supported.

An unexpected occurrence during recruitment was that people sometimes got in touch to ask where they could find information about diabetes and learning disabilities since they had not received information that they could understand from health services.

In addition to reviewing and adjusting the recruitment criteria for people with learning disabilities and their supporters as described above, queries received led to clarification of other project details in recruitment adverts and on the website including the definition of ‘learning disabilities’ and whether this included people with specific learning difficulties such as dyslexia.

3.4 Participants

Eleven participants with learning disabilities were recruited: four in response to recruitment details circulated by supported living environments, and seven via details circulated by three separate advocacy groups and subsequent snowballing. Six women and five men were interviewed, two had type 1 diabetes and nine had type 2 diabetes (see table 1 for full details). Interest was expressed by or on behalf of ten further people with learning disabilities: eight did not meet the recruitment criteria, two decided not to participate. Data from three interviews were subsequently excluded from the discourse analysis: two made insufficient contributions for discourse analysis and one participant did not describe any appointments or contact with healthcare professionals relating to diabetes.
Seven participants who support people with learning disabilities were recruited: five support workers, one former service manager and one advocate. Participants with learning disabilities identified six people who supported their diabetes appointments, four of whom agreed to take part in separate interviews (three support workers, one former service manager). Due to time constraints one further support worker (Lucia) declined to be interviewed separately but was present during the interview with the person she supported and gave consent for her contributions to be used in the research. Due to difficulties recruiting the minimum number for this participant group, recruitment criteria were reviewed and adapted to include one advocate who had supported one person with learning disabilities who declined to take part in the research (Jennifer) and separate interviews with a support worker and keyworker (Mark and Kamilla) who supported the same participant with learning disabilities (Patrick) (see table 2 for full demographic details). For two supporters (Kamilla and Lucia) English was a second language. Interest in the research was expressed by three further supporters: two were not eligible and one cancelled.

Five healthcare professionals with experience of at least one patient with diabetes and learning disabilities in a primary care setting were recruited (two advanced nurse practitioners, one nurse practitioner, one dietician and one GP). One healthcare professional was recruited through an email sent by the CCG’s Diabetes Programme Director and four responded to letters sent to general practices (see table 3 for full details). Two further healthcare professionals expressed an interest in the project but decided not to take part.
### 3.4.1 Demographic characteristics

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Sex</th>
<th>Ethnicity</th>
<th>Diabetes type</th>
<th>Time since diagnosis</th>
<th>Time since last primary care diabetes appointment</th>
<th>Nature of last appointment</th>
<th>Living Arrangements</th>
<th>Supportive other interviewed</th>
<th>Interview context</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>David</td>
<td>45</td>
<td>Male</td>
<td>White British</td>
<td>2</td>
<td>30 years</td>
<td>Unsure(^6)/ around 6 months</td>
<td>Diabetes review</td>
<td>Supported living</td>
<td>Care manager (Peter).</td>
<td>Kitchen of supported living house. Staff available.</td>
<td></td>
</tr>
<tr>
<td>Sue</td>
<td>49</td>
<td>Female</td>
<td>White British</td>
<td>2</td>
<td>8 years</td>
<td>5 months</td>
<td>Diabetes review</td>
<td>With husband</td>
<td>n/a</td>
<td>Office of self-advocacy group.</td>
<td>Active member of self-advocacy group</td>
</tr>
</tbody>
</table>

---

\(^6\) David reported it was ‘a long time ago’, support staff reported around 6 months.
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Duration</th>
<th>Diagnosis</th>
<th>Setting</th>
<th>Key Worker</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hayley</td>
<td>60</td>
<td>Female</td>
<td>White</td>
<td>3 weeks</td>
<td>Diabetes</td>
<td>Supported living</td>
<td>Sally</td>
<td>Living room of supported living environment. Supporter present.</td>
</tr>
<tr>
<td>Patrick (Excluded 7)</td>
<td>59</td>
<td>Male</td>
<td>White</td>
<td>4 months</td>
<td>Diabetes</td>
<td>Supported living</td>
<td>Mark and Kamilla</td>
<td>Offices of self-advocacy group. Supporter present.</td>
</tr>
<tr>
<td>Thomas</td>
<td>33</td>
<td>Male</td>
<td>White</td>
<td>2 days</td>
<td>Practice nurse (foot dressing)</td>
<td>With family</td>
<td>n/a</td>
<td>Offices of self-advocacy group. Active member of self-advocacy group</td>
</tr>
</tbody>
</table>

7 Speech difficult to understand & contributions too limited for discourse analysis.
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Length</th>
<th>Time</th>
<th>Diagnosis</th>
<th>Location</th>
<th>Support</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Melanie</td>
<td>43</td>
<td>Female</td>
<td>Black British</td>
<td>2</td>
<td>1.5 years</td>
<td>2 months</td>
<td>Diabetes review</td>
<td>Supported living</td>
<td>n/a</td>
</tr>
<tr>
<td>Christine</td>
<td>47</td>
<td>Female</td>
<td>White British</td>
<td>2</td>
<td>Unsure</td>
<td>Unknown</td>
<td>Unknown</td>
<td>With family</td>
<td>n/a</td>
</tr>
</tbody>
</table>
| Pauline       | 63  | Female | White British | 2      | About 10 years | 1 day | Blood tests | Supported living | Support worker (Karen) | Kitchen of supported living environment |}

8 Did not recall experiences of diabetes related appointments.
9 Insufficient verbal responses.
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Type 1 Diabetes Duration</th>
<th>Type 1 Diabetes Management</th>
<th>Health Professional</th>
<th>Type of Living</th>
<th>Setting/Staff</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>William</td>
<td>64</td>
<td>Male</td>
<td>White</td>
<td>British</td>
<td>5/6 years</td>
<td>Unknown</td>
<td>Supported living</td>
<td>n/a</td>
<td>Office of self-advocacy group.</td>
</tr>
<tr>
<td>Lynne</td>
<td>37</td>
<td>Female</td>
<td>White</td>
<td>British</td>
<td>Unknown</td>
<td>Diabetes nurse</td>
<td>Supported living</td>
<td>Support worker Lucia contributed to Lynne’s interview.</td>
<td>Living room of supported living environment. Staff present.</td>
</tr>
<tr>
<td>Simon</td>
<td>64</td>
<td>Male</td>
<td>White</td>
<td>British</td>
<td>2 months</td>
<td>Diabetes review</td>
<td>Supported living</td>
<td>n/a</td>
<td>Office of self-advocacy group. Advocate present for most of the interview.</td>
</tr>
</tbody>
</table>

nt. Staff present.

Active member of self-advocacy group.

Down’s Syndrome
Table 2. Supporter demographic details (real names replaced with pseudonyms)

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Sex</th>
<th>Job title</th>
<th>Time in job</th>
<th>Time spent working with participant with learning disabilities</th>
<th>Work environment</th>
<th>Supporting relationship</th>
<th>Role/experience supporting diabetes care appointments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sally</td>
<td>Female</td>
<td>White British</td>
<td>Support Officer</td>
<td>4 years</td>
<td>4 years</td>
<td>Supported living</td>
<td>Keyworker to Hayley (attends diabetes appointments only if requested).</td>
</tr>
<tr>
<td>Mark</td>
<td>Male</td>
<td>White British</td>
<td>Support Worker</td>
<td>2 years</td>
<td>2 years</td>
<td>Supported living</td>
<td>Supports Patrick (attends some diabetes related appointments).</td>
</tr>
<tr>
<td>Karen</td>
<td>Female</td>
<td>White British</td>
<td>Support Worker</td>
<td>6 years</td>
<td>6 years</td>
<td>Supported living</td>
<td>Supports Pauline (attends appointments).</td>
</tr>
<tr>
<td>Name</td>
<td>Gender</td>
<td>Ethnicity</td>
<td>Role</td>
<td>Length</td>
<td>Years</td>
<td>Service Type</td>
<td>Key Worker</td>
</tr>
<tr>
<td>--------</td>
<td>--------</td>
<td>-------------------</td>
<td>-------------------------------</td>
<td>--------</td>
<td>-------</td>
<td>-----------------------</td>
<td>------------</td>
</tr>
<tr>
<td>Jennifer</td>
<td>Female</td>
<td>White British</td>
<td>Advocacy Adviser</td>
<td>Unknown</td>
<td>1 year</td>
<td>Advocacy group</td>
<td>n/a</td>
</tr>
<tr>
<td>Peter</td>
<td>Male</td>
<td>White British</td>
<td>Care home owner/manager</td>
<td>30 years</td>
<td>30 years</td>
<td>Supported living</td>
<td>Formerly supported David</td>
</tr>
<tr>
<td>Kamilla</td>
<td>Female</td>
<td>White European</td>
<td>Support worker</td>
<td>6 years</td>
<td>5 years</td>
<td>Supported living</td>
<td>Patrick (also supported by Mark)</td>
</tr>
<tr>
<td>Lucia</td>
<td>Female</td>
<td>White European</td>
<td>Support Worker</td>
<td>Unknown</td>
<td>Unknown</td>
<td>Supported living</td>
<td>Lynne</td>
</tr>
</tbody>
</table>

10 English is second language
11 English is second language
Table 3. Demographic details of healthcare professionals (real name replaced with pseudonyms)

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Sex</th>
<th>Job title</th>
<th>Time in role</th>
<th>Time since last LD appointment</th>
<th>Work environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Linda</td>
<td>Female</td>
<td>Advanced Nurse Practitioner</td>
<td>20+ years</td>
<td>Less than 3 months</td>
<td>GP surgery</td>
</tr>
<tr>
<td>Alison</td>
<td>Female</td>
<td>Advanced Diabetes Dietician</td>
<td>10+ years</td>
<td>Less than 3 months</td>
<td>GP surgery and community</td>
</tr>
<tr>
<td>Amanda</td>
<td>Female</td>
<td>Nurse Practitioner (specialist interest in diabetes)</td>
<td>15+ years</td>
<td>Less than 3 months</td>
<td>GP surgery and previously in the community</td>
</tr>
<tr>
<td>Hilary</td>
<td>Female</td>
<td>Advanced Nurse Practitioner</td>
<td>30 years</td>
<td>Unsure</td>
<td>GP surgery</td>
</tr>
<tr>
<td>Dr Jones</td>
<td>Male</td>
<td>GP</td>
<td>20 years</td>
<td>6 weeks</td>
<td>GP surgery</td>
</tr>
</tbody>
</table>

3.4.2 Participant relationships

Four participants with learning disabilities were recruited in cases consisting of the person with learning disabilities and one or two paid carers. Multiple participants were recruited from the same two advocacy groups and therefore some participants were known to each other. Two healthcare professionals (Amanda and Dr Jones) worked at the same practice and thus discussed the same systems and patients. Although healthcare professionals were recruited separately from people with learning disabilities, it appeared that three healthcare professionals (Amanda, Dr Jones and Alison) described experiences with people with learning disabilities who had been interviewed as part of the study, but this was not verified.
3.5 Data Collection

3.5.1 Interview guides

Separate interview schedules were produced for participants with learning disabilities, supporters, and healthcare professionals (see appendix 12). Interview schedule design was informed by the literature on interviewing people with learning disabilities (Finlay & Lyons, 2001, 2002; Prosser & Bromley, 2012), recommendations for quality diabetes care (Diabetes UK, 2012; Turner, 2014) and the literature on the experience of diabetes/health services for all stakeholders (Cardol et al., 2012b, 2012a; Hale et al., 2011; Lennox et al., 2015). It was further informed by themes relating to experience of diabetes care appointments in the data from my MSc project which had included a short section of questions on this topic (Rouse, 2014). The interview schedule aimed to elicit the experience of primary care diabetes appointments including consideration of before, during, and after the appointment.

3.5.2 The interview procedure

All interviews were conducted by the researcher who is female and has experience of interviewing adults with mild-to-moderate learning disabilities and support staff. The researcher also has experience of living with and supporting family members who have type 1 diabetes.

3.5.3 The interview context

Participants were recruited from and interviewed in the South East and East of England. Interview locations were chosen in consultation with participants to ensure convenience and that participants felt comfortable. Interviews took place in private rooms/areas of supported living environments or the offices of advocacy groups for people with learning disabilities and supporters. Privacy was requested for the duration of the interview. Two supporters were interviewed in community environments separate from their workplace (Jennifer and Peter). All other supporters were interviewed immediately after the
individual they support and in the same location. Four healthcare professionals were interviewed within offices of the healthcare practices in which they worked and one within a university research office.

As outlined in the ethics section, participants with learning disabilities were given the opportunity to have someone they knew stay with them for all or part of the interview to help them to feel comfortable speaking to the interviewer. Four participants asked for their supporter (also interviewed) to be present for the whole interview, three people asked for advocates who do not directly support them in relation to their diabetes care to be present for all or most of the interview. One participant asked for support staff in the environment where they live to be available but not sitting in on the interview. Three participants opted to be interviewed alone.

3.5.4 Gaining informed consent

Previous health and social care research has found that offering audio versions of information sheets and/or the option to give verbal consent increases the inclusivity of research for populations who have difficulty with written information (Beadle-Brown et al., 2012; Ferrari, 2015; Lloyd et al., 2008; Paquin, Crawley, Harris, & Horton, 2016; Poland et al., 2014). Participants with learning disabilities were therefore offered the option to receive audio information sheets and to give verbal consent. All participants with learning disabilities chose to complete the written consent form developed with feedback from the advisory group (see appendix 13).

The interviewer went through each aspect of the information sheet and consent form step by step with participants with learning disabilities. Eight participants with learning disabilities had someone they knew with them whilst going through the consent process. Opportunities were given to ask questions throughout this process. The interviewer talked to the participant about the information sheet and consent form to help ensure understanding. It was made clear that they could choose not to take part even if their support staff thought it was a good idea. They were assured that their diabetes care would not be impacted in any way.

Informed consent was obtained for all participants prior to interviews. As per the legislative framework under the Mental Capacity Act (MCA), a presumption of capacity was
made, followed by a supported decision-making process to help the person decide if they wanted to take part in the research. This included the provision of accessible information and consent sheets for participants with learning disabilities developed with feedback from the advisory group; discussing issues with participants and supporters before recruitment, and then talking through the information sheet and consent form with the participant. I then asked questions to check if the person could understand the information; retain it; weigh up or use the information to make a decision; and then communicate their decision to take part (the Mental Capacity Act ‘capacity test’). On following this procedure, no participants were judged to lack the capacity to make the decision to take part in the research.

All participants gave informed consent immediately before the interview. Participants were asked to indicate on the consent form if they would like to receive a summary of findings at the end of the research.

3.5.5 Interviews

Where possible, the researcher spent time establishing rapport with participants prior to the interview by discussing interest in diabetes and other interests such as advocacy group activities. For some participants this involved visits to the advocacy group meetings to meet people and talk about the research. Initial questions on demographic details and general information were also designed to help ease into the interview. Participants were told that the researcher was going to ask questions and was interested in hearing about their experiences of diabetes primary care appointments (what happens in their appointments) and their views on quality (what they think is good or bad about their appointments). All participants were told that there were no right or wrong answers and that they could choose not to answer any question, to take a break or to stop the interview at any time. People with learning disabilities were told that we could look at pictures to help them to remember what happens in diabetes appointments.

Interview schedules for each participant group followed a broadly similar format, to allow for comparison during analysis. Schedules began with questions on demographic details and general questions to begin reflection and establish rapport. Questions were then separated into processes before, during and after appointments, views on quality of care
and views on responsibility for quality care. Prompts were used where needed. The interview schedules were semi-structured and thus guided interviews, but the exact wording and order of questions depended on the flow of the interview, responses and communication abilities. Adaptations were made to interview schedules based on reflection following early interviews. Visual prompts were used to support memory of participants with learning disabilities (see appendix 1) when considering procedures involved in diabetes care appointments. All interviews ended with an open question inviting comment on any aspect of the experience of diabetes primary care appointments for this population.

Interviews were recorded using a digital voice recorder and ranged in length from 11 minutes to 1 hour 30 minutes (a total of 18 hours 40 minutes of data). After the interview, participants were asked how they found taking part and were given the opportunity to ask any further questions about the research. All participants were given a copy of the signed consent form and offered a copy of the resources sheet (see appendix 14) which signposted sources of support and information about diabetes/adjusting diabetes appointments for people with learning disabilities. Participants with learning disabilities and supporters were offered a £20 gift voucher in recognition of their time.

3.6 Ethical Issues

In line with the British Psychological Society code for human research ethics, data was securely stored to protect confidentiality (BPS 2012). Efforts have been made to ensure interview transcripts were as anonymous as possible by replacing any names mentioned during interviews and any other potentially identifying information with pseudonyms or descriptions e.g. ‘doctor’s surgery’. This was made clear in information sheets and during the consent process to help participants to feel comfortable discussing the role of other stakeholders.
3.6.1 Ethical issues and participants with learning disabilities

It was possible that participants with learning disabilities would find the interview process tiring. Participants were told that they could end the interview or continue at another time. One participant (William) chose to end the interview early.

It was possible that participants with learning disabilities may feel uncomfortable being interviewed alone but may also find it difficult to freely share some views or experiences in front of their supporters. Participants with learning disabilities were therefore offered the opportunity to have someone they trust other than their carer sit in on their interview, or for their carer (or someone else who they trust) to be available nearby. If the participant with learning disabilities only felt comfortable to be interviewed with their supporter present, the interview went ahead with the supporter present but with the option that if the participant became comfortable enough to speak with the researcher alone their supporter may leave the room. The best situation to make participants comfortable was discussed with the participant and supporters (details of interview context in section 3.5.3).

Before starting the interview, it was made clear to all participants that they were free to withdraw from the study at any point and to ask for the audio recording and interview transcripts to be destroyed. The consent form and information sheet included details of different ways to withdraw from the study including a hard copy withdrawal form.

3.6.2 Ethical approvals and permissions

The project received a favourable opinion from the Open University’s Human Research Ethics Committee (see appendix 15). Consultation with local NHS R&D confirmed that since people with learning disabilities were not to be recruited through NHS systems or interviewed on NHS sites, additional NHS ethical approval was not needed for this group. This meant that University ethics approval was sufficient to recruit people with learning disabilities. However, in order to recruit and interview healthcare professionals who were NHS staff and to make use of NHS sites to conduct interviews, permissions were needed from the NHS Health Research Authority. Following a successful ethics application to the NHS Health Research Authority, a letter of approval was received, which allowed recruitment and interview of professionals by virtue of their role and on NHS premises.
within one East of England Clinical Commissioning Group (see appendix 16). A letter of
permission was also received from the local R&D office to approach primary care staff (see
appendix 17). The study was further reviewed and received approval from the Research
Governance Panel & Service Director for Adult Social Care at an East of England County
Council (see appendix 18), permitting recruitment and interviewing of people with learning
disabilities and supporters through council run services. Completion of separate
permissions to recruit Learning Disability nurses (employed by the local NHS health Trust
and not the CCG) were abandoned due to difficulty fulfilling the requirement of a Trust
employee to act as responsible person for the project. Learning disability nurses were
therefore not approached for recruitment.

Additional applications were completed, reviewed and received approval by Diabetes UK
and the Down’s Syndrome Association to enable recruitment support.

3.7 Data Analysis

Transcription and data analysis were ongoing alongside data collection.

3.7.1 Transcription

All interviews were transcribed verbatim by the researcher using a modified version of
Jefferson transcription (see appendix 19 for symbols). For example, underlined text
denotes emphasis on the whole or part of a word. In line with the aims of discourse
analysis, this system of transcription captures the messiness of speech and is appropriate
when speech is being researched as social action (Howitt, 2010, 2016a). Audible intakes
and outtakes of breath, laughing and coughing are noted since these non-word sounds are
sometimes used for communication. Since analysis for this project did not aim to explore
the finer grain details of interaction such as those involved in conversation analysis (e.g.
repairs, turn taking), a complete Jefferson transcription, including intonation and timed
pauses for example, was not conducted.

To help ensure confidentiality, participants and people they referred to were given
pseudonyms. Names of places were not transcribed but were described in the text e.g. ‘GP
surgery’. Transcription followed the three stages recommended by Howitt (2010;2016) of tuning into the recording, rough transcription and adding Jefferson transcription. Aspects of Jeffersonian transcription used were: overlapping speech, laughter and other non-words, emphasis, speech volume, latching and extra information (e.g. change of voice, indicating activity in the room). The talk of others captured by the recorder during interruptions to interviews (e.g. where other people entered the room) were marked as ‘interview interrupted’ in the transcript. In keeping with the argument that researchers should avoid spending time including details superfluous to the aims of their analysis (Howitt, 2016a), long sections of talk on topics unrelated to diabetes/health care were excluded from transcripts (this is marked on the transcript as ‘[…]’) and non-words judged by the researcher not to be communication (sneezing) were not included.

It should be acknowledged that despite the advantages of Jefferson transcription, this system does not capture facial expressions and body language well, meaning that the majority of nonverbal elements of the interactions were lost. Where participants’ use of gestures (nodding/shaking of the head, pointing and mimes) to communicate were noted in the research diary, this non-verbal communication has been indicated in the transcript, but accuracy could not be checked. Changes in tone of voice were also described in transcripts (e.g. angry, strict, bored) but inevitably bring in a value judgement by the transcriber.

3.7.2 Data included in analysis

As in previous discourse analysis studies with people with learning disabilities (Jingree, 2009; Jingree & Finlay, 2013), decisions were made to exclude two transcripts (Patrick and Pauline) from the analysis where the individual made insufficient contributions for discourse analysis to be conducted (incomprehensible or monosyllabic/nonverbal responses. One further transcript was excluded (Christine) because the participant did not describe any diabetes related appointments or contact with healthcare professionals.

Despite the methodological strengths of discourse analysis (as discussed in sections 3.2 and 8.3) it is important to acknowledge that the focus on talk means that discourse analysis of transcripts of audio recorded interviews had some ethical and methodological implications for this thesis. Discourse analysis requires adequate clear verbal contributions from
participants. For some people with learning disabilities such as those with speech
difficulties and/or whose communication included nonverbal gestures, this requirement
resulted in exclusion from the data analysis for this project. As well as the issue of
inclusivity, there are ethical questions around excluding data from participants who have
given their time to participate in the research. Further challenges were encountered
during the analysis of some transcripts where the verbal responses from people with
learning disabilities were brief or dominated by supporters. The limitations of interview
data and particularly studies employing discourse analysis in terms of the inclusion of
people with communication difficulties has been previously documented (Brewster, 2004;
Jingree, 2009; Nunkoosing, 2005). Alternative approaches to analysis which are less reliant
on adequate verbal contribution may support greater inclusivity. Examples include
approaches which enable the use of communication aids such as Talking Mats or which
incorporate aspects of nonverbal communication including gesture and body language such
as conversation analysis of video data (Brewster, 2004; Finlay, Walton, & Antaki, 2008;
Jewitt, 2012). Nevertheless, for this project, which aimed to recruit people with mild-to-
moderate learning disabilities, sufficient data were gained from eight participants with
learning disabilities to allow discourse analysis to be conducted.

Where supporters were present during the interview with people with learning disabilities
and had given consent, their contributions to interviews were transcribed and included in
analysis.

Despite emphasising the focus of the research on primary care appointments during the
recruitment and interview process, interviewees also talked of experiences of secondary
and community diabetes care, perhaps reflecting the interconnected nature of diabetes
care. These reflections were included in the analysis since they were often used to make
comparisons with primary care. In the analysis section, where participant reflections do
not refer to primary care, this is made clear in the text.

3.7.3 Data analysis strategy

Data analysis was undertaken by the researcher who has training and experience in the use
of social constructionist discourse analysis. Data analysis was guided by the advice of
(Taylor, 2001b) and (Edley, 2001) and followed Wetherell’s (1998) recommendations for
combining the study of culturally available discursive resources and the fine details of
discursive practices (Wetherell, 1998). Interviews were explored for the discursive
construction of quality diabetes care appointments and responsibility for quality appointments. Analysis included application of the following analytic tools:

**Interpretative repertoires:** this term refers to the culturally available shared common patterns and lines of argument that we use to construct the social world in everyday social interaction (Edley, 2001; Potter & Wetherell, 1987; Wetherell, 1998).

**Subject positions:** in the use of interpretative repertoires, speakers construct themselves and others as occupying particular categories known as subject positions (such as competent diabetes patient) (Potter & Wetherell 1987; Wetherell 1998; Edley 2001).

**Ideological dilemmas:** since speakers can draw on multiple contradictory repertoires within the same account, critical discourse analysis draws on Billig’s notion of ideological dilemmas to identify these contradictions and explore the ways in which conflicting ideas are managed by speakers in everyday talk (Billig, Condor, Edwards, & Gane, 1988; Billig, 2001; Edley, 2001).

Discourse analysis is an iterative process for which there is no commonly agreed procedure (Howitt, 2016c; Ussher & Perz, 2015). Data analysis included the steps: familiarisation, identification and coding of possible interpretative repertoires and subject positions relating to quality diabetes care and responsibility for quality care to develop an initial framework for coding, highlighting and coding of relevant text. Familiarisation began with listening to recordings shortly after each interview whilst noting initial thoughts relating to quality care and continued throughout transcription. Hard copy transcripts were then read and reread with the research questions in mind, with some returns to the audio recordings, highlighting and making notes on possible relevant interpretative repertoires and subject positions. Initial ideas were further developed and refined through organisation in the qualitative analysis software QSR NVivo 11. Preliminary repertoires were coded as nodes and sub-nodes in NVivo to help organise data and to support checking the fit of data to the repertoires and the appropriateness of repertoire descriptions (see appendix 20). This led to redefinitions of some repertoires and removal of others. Organising of data in NVivo followed the guidance of Silver and Lewins (2014) on software for qualitative data analysis including recording ongoing reflections and development of ideas in memos during analysis and keeping a reflective log of thoughts, questions, dilemmas and decision-making for transparency (Silver & Lewins, 2014). Once illustrative examples of repertoires and positions had been identified these were further analysed for the fine grain discursive
devices used to construct broader patterns and repertoires (Edwards & Potter, 1992; Potter, 1996; Potter & Edwards, 1999; Wetherell, 1998) and for inconsistencies and contradictions producing potential ideological dilemmas (Billig, 2001; Billig et al., 1988). Initial ideas were further revised in light of discussion with my supervisors and continued to be refined and clarified throughout the writing process. Transcripts were considered individually and then compared for commonalities and differences within and between stakeholder groups. Since one aim of the research was to identify similarities and differences between the discursive construction of quality care between stakeholder groups, focusing initial analysis within and then between stakeholder groups aimed to draw out any differences which may be lost when analysis of all transcripts is combined.

Consistent with the aims of critical discursive psychology, consideration was then given to:

- the actions performed by available discursive resources within the context of the interview
- how discursive resources are situated within the context of current diabetes care as well as wider available discourses about people with learning disabilities and their healthcare
- the implications of the ways in which stakeholders negotiate meanings of quality and responsibility for primary care diabetes care services for people with learning disabilities
- their contribution to power relations between stakeholders.

3.8 Quality checks

In qualitative research the validity of analysis is often assessed through its goodness of fit with the data (Howitt, 2016b). This was checked and rechecked and repertoires were redefined as described in section 3.7. Attempts were made to ensure the validity of transcription through multiple readings, checking against the original recordings and referring back to the audio recordings during analysis. As recommended by Howitt (2016), my methods of data collection, transcription and analysis have been made explicit during this chapter.

Inclusion of inconsistencies and deviant cases is important in assessing quality of qualitative research (Howitt, 2016b) and discourse analysis in particular (Taylor, 2001a). I have
incorporated and attempted to explain deviant cases in my findings chapters. So that my interpretation and analysis are open to evaluation, I have presented data in the analysis section to support my analytic interpretations.

Analytical progress, decision-making and developing ideas were recorded throughout the analysis in NVivo to support transparency and contribute to validity (Silver & Lewins, 2014). To help ensure credibility of the analysis, preliminary analysis of transcripts from each separate stakeholder group was discussed with my supervisors and revised based on their feedback. Preliminary discourse analysis findings were presented and received feedback from students and academics at a faculty research event and from colleagues at the Faculty’s health study research group. Validation by participants or individuals comparable to participants has been cited in quality criteria for qualitative research allowing discussion and questioning of findings (Howitt, 2016b; Mays & Pope, 2000). Presentations on preliminary findings leading to discussion on preliminary findings were given at two separate events aimed at women with learning disabilities, support staff and healthcare professionals.

A proposed quality criteria for discourse analysis is the extent to which the research provides novel explanations and provides a basis for future research (Potter & Wetherell, 1987; Taylor, 2001a). This research provides novel explanations for the maintenance/production of inequalities and the use of discursive strategies within the context of talk on quality diabetes care for people with learning disabilities as described in the findings chapters. It also suggests further research as described in chapter 8.

3.8.1 Reflexive analysis

Reflexivity is a quality criteria of qualitative research – the researcher should make clear their own experiences, attitudes and values which may impact on analysis and their social distance between the researcher and participant (Howitt, 2016b; Mays & Pope, 2000). Following each interview, I made reflexive notes in a research diary. I recorded my initial thoughts immediately after each interview then listened to the interview for further insight and reflection on how the interview went. I then added to these whilst listening to and transcribing the interviews. Reflections on how the interviews went were used to feed into and improve subsequent interviews by adapting technique and by considering which questions worked well/less well and led to some adaptations to the interview guides. As recommended by Howitt (2010) and Gough and Madill (2012) I then used my notes to
produce a reflexive account of my own impact on data collection, analysis and interpretations and made my own experiences and biases relating to the topics and participants clear (see appendix 21).

3.8.2 Impact

Comments during and after interviews noted in my research diary include that participants had previously been unaware of documents aimed at people with learning disabilities and Diabetes UK 15 healthcare essentials and would look these up. People with learning disabilities and supporters said that as a result of the interview they planned to ask their doctor about topics they had not previously considered raising during appointments or where they had not previously received a satisfactory response e.g. diet, education and emotional aspects of diabetes. Preliminary findings from this thesis have been presented at a user-led event on the health of women with learning disabilities and at a diabetes care event for support workers and healthcare professionals. Following a presentation of my research, support workers said that they would incorporate information from the presentation into their work with people with learning disabilities and diabetes. Findings from my thesis have also fed into the development of guidelines for reasonable adjustments in the diabetes management of type 2 diabetes for adults with learning disabilities (International Association for the Scientific Study of Intellectual & Developmental Disabilities Health Special Interest Research Group, 2019).

3.9 Chapter summary

This chapter began by describing the social constructionist theoretical framework that underpins my thesis. It also detailed my methodological procedures covering recruitment, study design, data collection and data analysis and explained the rationale for my chosen methodology. This included detailing the choice and context of semi-structured interviews and visual prompts. It also outlined the patient and public involvement initiatives and the ways in which feedback from the learning disability advisory group was incorporated into my research design. As in all research, a number of challenges arose whilst conducting the project. To address these issues as they arose it was necessary to review and adapt
recruitment criteria and the interview context to meet the needs and concerns of participants. This chapter has briefly reflected on some of the challenges that occurred during the recruitment process and how these challenges were managed.

I have described the ethical issues relevant to my research and the measures taken to ameliorate these. The chapter highlights how I addressed ethical issues specific to recruiting and interviewing people with learning disabilities. I have also described the steps taken to ensure quality and rigor in my research. Finally, I have reflected on the impact of my own experiences and biases on the research and the impact of the research so far. The next three chapters present the findings of my analysis of the data for each stakeholder group: people with learning disabilities, supporters and healthcare professionals.

Chapter 4 Findings i) - The construction of quality diabetes primary care appointments by adults with learning disabilities

This chapter focuses on the analysis of eight interviews with adults with mild-to-moderate learning disabilities. Although participants were asked to reflect on their most recent primary care diabetes appointment, some also brought in their experience of secondary care (e.g. experience of hospital consultants). Where an excerpt considers secondary care, this is highlighted in the text.

Overview

In order to construct the quality of their diabetes care appointments, participants drew on a number of socially available ideas or interpretative repertoires about: the purpose of diabetes care appointments, the roles and responsibilities of themselves and other key stakeholders within these appointments (healthcare professionals, practice staff and those who provide support e.g. family or paid carers) and ideas on what constitutes a difficult or easy appointment experience. This chapter is therefore structured according to the key repertoires: i) constructing the purpose of diabetes primary care appointments, ii) roles and responsibilities and iii) repertoires of difficulty. These three sections are further
divided to illustrate different ways in which each repertoire was constructed and the varying ways in which participants with learning disabilities positioned themselves and others within these repertoires. How each repertoire constructs quality primary care diabetes care appointments and the management of conflicting repertoires is also considered.

4.1 Constructing the purpose of diabetes primary care appointments

All participants drew on the repertoire that diabetes care appointments have aims that should be fulfilled when constructing the quality of their appointments. Participants drew on two key ideas about the purpose of diabetes appointments which are reflected in the two main sub-sections here: i) that diabetes appointments inform people with diabetes about their condition and ii) that appointments involve the monitoring of their diabetes management by healthcare professionals.

4.1.1 Appointments as informative

Participants constructed providing information to the person with diabetes in order to enhance/inform their day-to-day diabetes management as an important purpose of primary care diabetes appointments.

All participants with learning disabilities regularly constructed providing information to themselves (the person with diabetes) as an important purpose of primary care diabetes appointments. Some also drew on the idea that this information should give them a good understanding of diabetes and how to look after themselves in order to improve or simplify their day to day self-management of the condition.

4.1.1.1 Flawed information

Whilst all participants drew on the idea that the aim of diabetes appointments is to inform, four participants did so by clearly constructing difficulties with the information they receive (information that is absent, incomplete, inconsistent, inaccurate or inaccessible) as constituting a flaw in their appointments. In the extract below, Sue who has type 2
diabetes, lives with her husband and is a member of a self-advocate group, constructs provision of information as an important purpose of diabetes appointments, making the incomplete information that she receives a cause for complaint.

**Extract 1**

210 **Interviewer:** So when you’re preparing to go to an appointment do you ever um write down any questions you might want to ask when you’re there?

212 **Sue:** No not usually. I should but I don’t (laughter).

213 **Interviewer:** Do you think it would be helpful if you did?

214 **Sue:** Um it would be helpful to know - like I only know that diabetes can be dangerous and gives you blood clots and leg ulcers and stuff like that and it’s not good for your heart but the diet it - I don’t get any of that information about what I’m supposed to eat and what I’ve got to cut but I know it’s sugar mostly but other stuff like fats and stuff I don’t know nothing about and they don’t explain them bits to me.

... 

228 **Sue:** No I think they’re supposed to get me into a (.) a course thing? like a diabetes course or something but that hasn’t happened yet, unless I’ve missed it and forgot all about it (laughter) but I need to chase it up and find out what’s been happening.

(Sue, lines 210-231)

Sue constructs improving understanding of diabetes as a purpose of her appointments and the lack of information questions the quality of her appointment. Throughout this extract, attributions of responsibility for ensuring that appointments are informative shift. Sue is responding to a question about whether she writes down any questions she wants to ask to prepare for the appointment. In stating that ‘I should but I don’t’ (212) followed by laughter Sue positions herself as at least partially responsible for gaining information from her appointment and as remiss for neglecting to do so. As Sue moves to describe the information she would like to know but has not been given, there is a shift in attribution of responsibility using a change of footing (Goffman, 2001) from ‘I should’ to ‘they don’t explain it to me’. The onus to ensure the appointment is informative has shifted from Sue (‘I’) to the healthcare professionals (‘they’) who have neglected to provide Sue with
information that ‘it would be helpful to know’ (214). Sue draws on the idea that there is a right way for people with diabetes to manage their diet (foods they are ‘supposed’ to eat or ‘cut out’) and that this knowledge is held by healthcare professionals (216-219). Towards the end of the extract, Sue positions professionals as responsible for improving her understanding of her diabetes by again referring to something professionals are ‘supposed’ to do (228-229). Sue ends by positioning herself as responsible to chase up the professionals about a course (230-231). This constructs Sue as having some responsibility to ensure she gets the information that she needs.

Sue positions herself as partially knowledgeable, demonstrating her awareness of the possible serious long-term consequences of diabetes (214-218) but constructs her knowledge as incomplete ‘I only know…’. Sue lacks understanding of diet – a lack of knowledge that impacts on her more day to day management of the condition. She knows she should cut some things out ‘sugar mostly’ but fats and other unspecified details of the diet ‘and stuff’ are uncertain. Detailing what she does know avoids an entirely ignorant identity and constructs her as capable of understanding and learning. What she lacks is specific information from professionals. In foregrounding her description of the information she lacks with her knowledge of the possible serious consequences, Sue also builds a case that diabetes is a serious condition (it can be dangerous, give you blood clots and be bad for your heart) using extreme case formulations (Edwards, 2000; Pomerantz, 1986) to strengthen her complaint that not being given the information to manage it is a serious flaw in her appointments.

4.1.1.2 Successful appointments improve understanding of diabetes

The extract below also demonstrates the idea that the purpose of appointments is to improve understanding of diabetes. In contrast to Sue in extract 1, Melanie constructs her most recent diabetes review as successful since it improved her understanding of diabetes. Melanie has type 2 diabetes and lives in a supported living environment.

**Extract 2**

636  Melanie:  It (diabetes review) just made me understand more about the diabetes and what’s good for me and what isn’t good for me and what can happen if you eat the wrong stuff all the time.

637

638

Interviewer:  Okay so did they talk to you about what could happen?
Melanie: Yes
Interviewer: Okay
Melanie: they said you can go blind or lose your limbs.

(Melanie, line 636-642)

Extract 3

Interviewer: Is there anything else that you find useful about your appointments?
Melanie: Just to try and understand it. I've got it for life and (.) I have to look after myself.

(Melanie, line 700-703)

Melanie is responding to a question about how her appointment changed how she looks after her diabetes. The question itself draws on the repertoires that people with diabetes are expected to be self-managing and that a purpose of appointments is to inform day-to-day diabetes care. In her response, Melanie does not detail any changes to specific tasks or her daily management. Instead, she highlights that what she has gained from the appointment is a better understanding of diabetes (636-638). This constructed improved understanding of diabetes as an important purpose of appointments.

As in extract 1, Melanie draws on the idea that there is a right and wrong diet for someone with diabetes which more knowledgeable healthcare professionals know and people with diabetes need to understand/be told about. It is made clear that it is Melanie herself who needs to have an improved understanding of diabetes (702-703). In the second quote Melanie clearly places the responsibility for daily diabetes care with herself, the person with diabetes. It is Melanie who must ‘try and understand it’ because ‘I have to look after myself’. The purpose of the appointment is to help her to understand diabetes so that she can look after herself. Melanie positions herself as realistic, knowledgeable and responsible for her own health – she is aware she’s ‘got it for life’ and responsible for trying to understand and look after it. She is also proactive, making an effort to ‘try and understand it’. These positionings of personal responsibility to understand and manage her condition may function to avoid the potential (and perhaps common) positioning of people
with learning disabilities as different from other people with diabetes and entirely dependent on others to manage their condition.

Melanie positions herself as having an improved understanding of diabetes following the appointment, constructing understanding as open to change and positioning Melanie as competent to learn, understand and improve her diabetes management. Extreme case formulations (Pomerantz, 1986) are used to explain why having a good understanding is important ‘all the time’, ‘you can go blind or lose your limbs’. The appointment is constructed as doubly effective: it has informed Melanie of what is and isn’t good for her and information acts as a warning about the serious potential consequences of losing her sight or a limb. As in extract 1, this constructs diabetes as something that needs to be taken seriously, possibly explaining why being well-informed is necessary. Therefore, appointments were constructed as flawed if they did not include the information needed to help the person understand and manage their diabetes effectively but good/useful if they improved the person’s understanding of their condition.

4.1.1.3 Information as unwelcome

Although participants commonly constructed the provision of information as an important and useful/positive purpose of appointments, two participants (Thomas and Lynne) drew on the idea that although the appointments are informative, information can be unwelcome. Lynne has type 2 diabetes managed with insulin and lives in a supported living environment. A support worker was present during this part of her interview.

Extract 4

934 Interviewer: Yeah so this is what you were saying ((looking at visual prompt))
935
936 Lynne: Oh here we go (laughter) yeah that one yes.
937 Interviewer: about getting advice about your diet.
938 Lynne: Yeah ((changes voice)) ‘that’s bad, that’s good’ ((pointing at images of unhealthy and healthy food)).
939
940 Interviewer: That’s it (laughter). So that’s what everyone’s telling telling you but it’s hard to follow isn’t it?
Lynne: It’s hard and I don’t - and I love fruit juice (.) that ((pointing at visual prompt)) and I can’t have it.

Interviewer: So who is it just the dietician who gives you advice about your diet or does anyone else?

Lynne: Everybody including my family.

Interviewer: Everybody and your family.

Lynne: Yeah it’s circle, circle, circle, circle.

Interviewer: Yes

Lynne: hhh

(Lynne, line 934-950)

This quote comes from discussion of the visual prompt showing illustrations of diet using pictures of unhealthy and healthy foods. Lynne has mentioned earlier in the interview that she finds it difficult to follow advice relating to diet. Here, Lynne constructs information given in appointments as familiar, repetitive and unwanted by expressing frustration: ‘oh here we go’. At line 938-939 Lynne changes her voice when demonstrating her knowledge of healthy food: ‘that’s bad, that’s good’, mimicking the repetitive advice that she has been given by others. In her use of reported speech which is also acted out (change of voice) she adds an evaluative account (Bakhtin, 1981, as cited in, Maybin, 2001) that this information is unnecessary. It is information that Lynne has heard before. She further expresses her frustration when she says ‘it’s circle, circle, circle, circle’ and with a sigh at line 950.

As with the examples above, Lynne is drawing on the idea that there are things that people with diabetes should not eat (938-939) and positions others (946) as knowledgeable about diabetes and in an advisory, informing role. However, Lynne constructs herself as already knowledgeable about diet, demonstrating her understanding by indicating unhealthy and healthy foods on the visual prompt and stating ‘that’s bad, that’s good’. This constructs the continuous circle of advice that she receives (line 948) during appointments and from others as unnecessary. It also constructs her as partially competent; she understands and remembers the advice but finds it difficult to put into practice (942-943). The information she receives is unwanted because it is repetitive and means there are things she wants but ‘can’t have’ and so ‘it’s hard’ to follow.
Within this repertoire people with learning disabilities positioned themselves as responsible for the self-management of diabetes and placed healthcare professionals in an informing/advisory role. Appointments which did not provide the necessary information for self-management were constructed as of questionable quality whereas a good appointment improved understanding and possibly management of the condition.

4.1.2 Appointments as assessment

A recurring repertoire in all of the interviews was that the purpose of appointments is for healthcare professionals to assess how well diabetes is being managed.

4.1.2.1 Assessments/test results demonstrate that you are doing well

All people with learning disabilities drew on the idea that appointments include assessments. Six participants drew on the idea that assessments demonstrated that they (the person with diabetes) were doing well with their diabetes management.

This included reporting that healthcare professionals were pleased with the test results and there was no need to change the way they were currently managing their diabetes (such as making changes to medication). In the extract below, to answer the question what is good about her appointments, Hayley highlighted that the doctor says her test results are fine and there is no need to make any changes to her insulin. Hayley has type 1 diabetes and lives in a supported living environment.

Extract 5

14  Hayley:  ...I went to see Dr Robinson he does diabetic - he’s a diabetic doctor
15  and he’s a - he just - he said ‘everything is fine’. My blood tests are
16  fine and er my uri- my blood sugar is fine
17  ...
18  Interviewer:  Was there anything good about it (last appointment)?
19  Hayley:  Er it’s g- they said it that it was good about it yeah
20  Interviewer:  Yeah
Hayley constructs her appointment as an assessment by the doctor who tells her that her test results are 'fine'. In lines 14-16, Hayley reports the speech of her doctor, first clarifying his area of expertise, which lends weight to her account 'he's a diabetic doctor'. The reported speech of an authoritative figure is difficult to refute (Bakhtin, as cited in Maybin, 2001). As a diabetic doctor his interpretation of her results is demonstrated to be reliable. The doctor is positioned as knowledgeable and authoritative in that he is the person able to assess the test results and make the judgement that 'everything is fine'. Hayley repeats 'fine' four times and gives a three part list of specific examples of what is fine, (her urine, blood sugar and kidneys) 'they’re all fine'. The inclusion of these details gives credibility to her account. In working to construct her test results as good, Hayley positions herself as a competent ‘diabetes patient’, the test results demonstrate she is doing well.

At lines 21-22, in response to a question on what was good about her recent appointment, Hayley responds that her insulin did not need to be changed. This again contributes to the positioning of Hayley as a successful, competent ‘patient’, her diabetes management must be going well since ‘they’ (knowledgeable professionals) have not made any changes. It implies that her self-management has been assessed as doing well. A good appointment is therefore constructed as one which does not result in change to the day-to-day management of diabetes, confirming that current management is successful.

4.1.2.2 Managing problematic results

Participants did not describe examples of disapproval or criticism from healthcare professionals about their test results. This may reflect the idea found in the talk of supporters and professionals that appointments for people with learning disabilities should be a positive and encouraging experience (discussed further in chapters 5 and 6). Two participants discussed examples of test results that could be considered unsatisfactory. When this issue was raised, participants defended their identity as competent, successful
‘diabetes patients’. In the following extract, Sue is responding to a question about whether her blood pressure is checked.

**Extract 6**

678  Sue: Yeah they do that. Sometimes mine’s high, sometimes it’s=

679  Interviewer: =Is it?

680  Sue: yeah it’s - sometimes it goes a bit high that’s because it’s only

681  because I’ve gotta walk from home to the doctor’s surgery so by

682  the time they’ve did my blood pressure it’s - I’m all out of breath

683  and my blood pressure’s up obviously and I think ‘well it’s only

684  because I’ve just walked from home to here that it’s up, why don’t

685  you just wait a minute? It’ll probably down in a minute’ (laughter).

(Sue, line 678-685)

Here Sue has described her blood pressure as sometimes high and quickly goes on to explain this in a way that does not suggest a poor result (lines 680-685). ‘It’s only because I’ve just walked from home to here that it’s up’. Repeated use of the moderating words ‘sometimes’, ‘a bit’ ‘it’s only’ along with Sue’s alternative explanation (her blood pressure is high due to walking) minimises the seriousness of this result (Potter, 1996). Sue also builds an account which questions the accuracy of the result. She describes it as ‘obvious’ that her blood pressure will be up in this context. The healthcare professionals are positioned as flawed and lacking in understanding here since they could easily ‘just wait a minute. It’ll probably be down in a minute’. Sue builds a strong account that the high reading is inaccurate, giving detail and reporting her thoughts to add strength to her alternative account of the results as temporary and contextual. If the high blood pressure reading is a result of professionals taking the reading at the wrong time (when her blood pressure is temporarily up) cause for this result is situated outside of herself and outside of Sue’s control. This defends against the accusation that a poor result is due to any poor health management on Sue’s part.
4.1.3 Other sources of support/topics beyond the role of appointments

Participants sometimes described alternative ways of accessing the assessments and information that would usually be part of a diabetes review appointment. They described sources of support in these matters that they used in addition to or instead of their primary care practices. This sometimes meant that covering these tasks or topics within primary care diabetes appointments was not constructed as important or was constructed as beyond the purpose of these appointments.

All eight participants drew on the repertoire that not all care processes were within the remit of diabetes primary care appointments. Participants described other sources as first choice over their GP for a number of processes that would typically be covered in primary care, including: blood pressure tests, flu vaccinations, learning about diabetes and advice about diet. Other sources included council, pharmacy, the gym, Diabetes UK, support staff and friends.

Participants who lived in supported living environments often positioned paid carers as an alternative and/or primary source of information for topics not covered during appointments. For example, Melanie described her support worker as her primary source of dietary advice.

**Extract 7**

467 **Interviewer:** You haven’t been given any ((dietary)) advice at all?

468 **Melanie:** No

469 **Interviewer:** That’s quite surprising isn’t it really?

470 **Melanie:** Yeah mmm

471 **Interviewer:** Do you think it would be useful?

472 **Melanie:** My carer Jane, who’s my support worker in the house she sat me down last Friday last week or Thursday and we went through my diet and she was telling me just have three jellies a night and one packet of crisps a night and that’s enough.

476 **Interviewer:** Yes
Instead of eating three packets of crisps, three jellies, three yoghurts, three chocolate bars, three bits of toast — too much I kept eating too much so I cut it right down now. I just have three jellies a night and two of those little Baby Bel cheeses?

Interviewer: Oh yes.

Melanie: yeah I have those at night.

Interviewer: Do you know how your staff knows about diabetes?

Melanie: They must be trained in it I don’t know.

Interviewer: Oh okay, maybe. Yeah but the doctor hasn’t - the nurse hasn’t talked to you about it?

Melanie: "No"

(Melanie, line 467-488)

Melanie constructed dietary advice from appointments as unnecessary, by positioning her support worker as fulfilling this role (472-475). The details included in Melanie’s account demonstrate her knowledge and understanding of the discussion and strengthen her story. Advice was constructed as successful by describing the subsequent improvements she has made to her diet: ‘I cut it right down now’. This positions Melanie as competent to learn and make improvements. Staff are constructed as knowledgeable to advise on her diet (more knowledgeable than Melanie) and in an advisory role, although how/why they have this expertise is uncertain (485).

The interviewer implies some criticism of appointments for lack of dietary advice (line 467-469). Melanie does not follow up on this but instead describes the role of her support worker. Melanie does not question or imply criticism of professionals for not offering dietary advice, her support worker’s help is successful, making professional advice unnecessary. This contrasts with Sue in extract 1 who positions primary care professionals as blameworthy for not giving her dietary advice.

The repertoire that primary care support was redundant/unnecessary was often drawn on to explain why appointments did not cover areas of the Diabetes UK 15 healthcare essentials unrelated to assessment, such as sexual health, pregnancy and emotional
support. These three topics were sometimes constructed as beyond the remit of primary care diabetes appointments.

Extract 8

1208 Interviewer: Um has your doctor ever asked you if you need any kind of emotional support so for example if you feel sad about diabetes and wanted someone to talk to?

1211 Thomas: No

1212 Interviewer: No

1213 Thomas: but (pause)

1214 Interviewer: Do you think that would be useful

1215 Interviewer: Do you think that would be useful

1216 Thomas: I I’ve not spoken to anyone about my diabetes apart from my mum and my, the family. How do you say, I’ve grown up with it since I was very small so I cause I sort of really know how I feel on a day to day basis. If I don’t feel what’s the word? at least a hundred and ten per cent a day I will always say to myself to stay in

1221 Interviewer: Yeah yeah

1222 Thomas: but I - really the talking to people and about it is not my sort of thing

(Thomas, line 1208-1223)

In relation to the emotional impact of diabetes Thomas positions himself as self-managing with some support from family (1216-1217). Thomas also positions himself as partly self-reliant. He is experienced and knowledgeable with an instinctive understanding of his own feelings (1217-1220) - a positioning previously identified when people with learning disabilities discuss diabetes (Rouse & Finlay, 2016). Thomas demonstrates his knowledge with an example of what he would do if not feeling right ‘I will always say to myself to stay in’. Emotional support from the appointment is therefore unnecessary. This is partly due to an internal personality related reason that is not open to change ‘talking to people about it is not my sort of thing’.

Whereas information (e.g. about diet) and assessments (e.g. blood pressure) were varyingly constructed as within or beyond the remit of primary care appointments, topics such as
emotional support were never unequivocally constructed as the purpose of these appointments and were usually constructed as outside of the role of healthcare professionals. This reflects previous findings that people with learning disabilities position healthcare professionals in a peripheral role in relation to the tasks of diabetes care (Rouse, 2014).

Summary of 4.1

Participants with learning disabilities drew on two key repertoires relating to the purpose of their diabetes primary care appointments: to inform people with learning disabilities on diabetes and its management to help them to self-manage their condition outside of the appointment and to assess ongoing diabetes management. Appointments which achieved the purpose of improving the person’s understanding of their diabetes care were constructed as successful. Where appointments were described as failing to inform (fully, clearly or at all) the individual about diabetes care, the appointment and/or systems, practice staff and health care professionals were positioned as at fault and failing in their responsibilities.

When describing the purpose of appointments as assessment/monitoring of their diabetes, participants did not describe experiences of failure to carry out assessments or fully complete specific assessments e.g. blood tests. Rare descriptions of test results that were judged problematic were presented in a way that defended against any implication that this was due to poor management by the participant. Appointments were constructed as good experiences where they confirmed that the person was doing well in their self-management outside of the appointment. It is striking that for people with learning disabilities it was not the carrying out of tests/assessments that defined the quality of an appointment but whether these results as interpreted by professionals, confirmed that things were going well.

Whether participants considered neglecting to cover any of the recommended care processes as cause to question the quality of their appointment depended on whether they constructed the task as within the remit of the appointment or as something that could be/is covered by other sources of support such as paid carers or family and friends. If this was an area already successfully covered, for example by support staff, then covering the same topic within primary care appointments was constructed as unnecessary. Care
processes most regularly constructed as beyond the role of primary care appointments were: sexual health, pregnancy and emotional support. If a topic was constructed as outside the remit of an appointment, then not covering it did not question the quality of that appointment.

4.2 Roles and responsibilities – overview

All stakeholders were constructed as having roles and responsibilities in relation to quality diabetes care. Participants with learning disabilities positioned themselves and others in relation to the roles they are expected to play and often assessed quality according to whether or not these roles were fulfilled. Good care involved people doing what they should, and it was a cause for complaint when they did not.

4.2.1 Constructing the role of the ‘patient’

People with learning disabilities often constructed themselves as ‘patients’ and as having the responsibilities attendant to this identity/categorisation. However, the role of the ‘patient’ was variously constructed as active or passive, conferring different responsibilities on the person with learning disabilities and healthcare professionals.

4.2.1.2 People with learning disabilities as proactive and knowledgeable

People with learning disabilities positioned themselves as proactive, self-managing and responsible ‘diabetes patients’. They positioned themselves (and other people with diabetes) as responsible to take an active part in their diabetes care appointments (and in their diabetes care more broadly), including communicating with the doctor, raising complaints and participating in assessments. Within this repertoire, appointments and assessments were not described as done to the person but involving cooperation and effort on the part of the person with diabetes.

The repertoire that the person with diabetes should take an active part in their diabetes care appointments was commonly drawn on and was present in all eight interviews. Although it was used in relation to all elements of the appointment, it was most frequently
used in accounts of interactions with healthcare professionals. In the extract below, Simon explains the importance of communicating with healthcare professionals, positioning himself in a proactive role.

Extract 9

1233 Interviewer: ...how do you find talking to your doctor?

1234 Simon: Talking to the doctor (pause) um sometimes we know more
1235 than what the doctor does don’t we?

1236 Michelle: Mmm

1237 Interviewer: Yeah

1238 Simon: Sometimes you have to tell them how you feel. If you
1239 don’t

1240 Interviewer: Yeah yeah

1241 Michelle: That’s a good point isn’t it?

1242 Simon: they’ll ask you a lot of questions don’t they?

1272 ...

1273 Simon: If you don’t if you don’t talk and listen to them it’s no good is
1274 it?

(Simon, line 1233-1274)

Simon distinguishes between himself/people with diabetes (‘we’/’you’) and professionals (‘them’/’they’) by changing pronouns and aligns himself with people with diabetes. Underlining of ‘them’ denotes that Simon emphasised this word. This type of categorisation of people into ‘we’ and ‘they’ is a persuasive way of ordering the world (Horton-Salway, 2001) and describes entitlements/characteristics of category members (Potter, 1996), in this case that the category ‘diabetes patient’ is associated with experiential knowledge that the doctor does not possess. Simon positions himself and other ‘diabetes patients’ as more knowledgeable than doctors: ‘sometimes we know more than what the doctor does’. This is similar to previous findings of people with learning disabilities constructing themselves as knowledgeable about diabetes based on experience of their body (Rouse, 2014; Rouse & Finlay, 2016). Simon positions himself/other people
with diabetes as responsible to take an active part in communication with the doctors to make the appointment worthwhile, arguing ‘you have to tell them’, and ‘if you don’t talk and listen to them it’s no good’. The ways in which it is ‘no good’ are not specified. The implication is that this is well known/common sense. Simon implicitly positions himself as competent to recognise how he feels, judge when to share this information and to communicate this information to the doctor. Simon also positions himself as knowledgeable about the appointment procedure and his role in the process. He has the experience to know that he needs to inform the doctor and what will happen if he does not: ‘they’ll ask you a lot of questions’.

Some participants constructed taking a proactive role as important by describing this as desirable even if it is difficult. Below, David constructs asking questions during appointments as difficult but important.

**Extract 10**

243 **Interviewer:** Is there anything difficult about talking to the doctor?

244 **David:** Erm questions probably.

245 **Interviewer:** Oh questions.

246 **David:** It’s asking questions, no (.) I suppose it’s *good*. I like to ask questions really it’s better (.) and ask all the answers. Maybe people I know I probably would you know what what it means.

(David, line 243-248)

David starts by constructing asking questions during appointments as difficult ‘*erm questions probably*’ and positioning himself as implicitly lacking in competence in this area. David quickly questions this (246-247) then aligns himself with this new construction of asking questions ‘*I like to ask questions really it’s better*’. David upgrades from ‘*I suppose*’ to the more confident ‘*I like*’, demonstrating that asking questions is something he does, despite the difficulty. Then he explains why it is good to ask questions ‘*to ask all the answers*’. This draws on the idea that as someone who is self-managing his condition, David needs to be informed about diabetes (as discussed in section 4.1.1). At line 247-248 David questions his competence to ask questions, adding he might ask questions if he knows the person. This section is a little unclear but possibly addresses his original statement that asking questions is difficult, in light of his potentially conflicting positioning, that asking questions is ‘*good*’ and ‘*better*’ and he ‘*likes*’ asking questions. It is difficult to ask questions but important and
possible with professionals he is familiar with. This performs identity work, defending against the potential assumption that he does not ask questions (he has said it is difficult) when he has built the case that asking questions is important.

4.2.1.3 Passive ‘patients’ and decision-making professionals

A potentially conflicting repertoire found in the talk of participants with learning disabilities was that healthcare professionals and practice staff give instructions which the person with diabetes follows. This repertoire was variously drawn on by participants to construct themselves as compliant or powerless. Within this repertoire healthcare professionals were positioned in an instructing role and the role of people with diabetes was to listen and put the information into practice.

This repertoire was present in almost all (7/8) of the interviews but was drawn on less commonly than the ‘proactive patient’ repertoire. In the examples below, in contrast to what might be expected given the strong repertoire that people with diabetes should be proactive, being in a passive position was not constructed as cause for complaint but was instead part of the ‘patient’ role.

Hayley described her doctor as making medication related decisions. Like other people with learning disabilities, when positioning herself as passive, Hayley drew on the idea that professionals make decisions that are for the best.

**Extract 11**

157 Hayley: What my sugars have been yeah yeah.
158 Interviewer: Do you talk to the doctor about that?
159 Hayley: Yeah I do, if it’s high and everything he said er well er er he doesn’t want to increase it again because it might have - could have hypo or something like that or=
160
161 Interviewer: =Oh
162
163 Hayley: yeah yeah=
164 Interviewer: =if he increases the insulin?
165 Hayley: If he increases the insulin yeah.
Here, talking to the doctor involves being told what will happen regarding her medication. Hayley describes what her doctor has said about her high blood sugar levels. Although Hayley has started by introducing this as an example of when she talks to her doctor about her blood sugar levels (‘yeah I do if it’s high and everything’) she quickly shifts to describing a scenario in which she has no input herself: ‘he said er well er he doesn’t want to increase it (insulin)’. This demonstrates a potential ideological dilemma (Billig et al., 1988): it is simultaneously desirable for the person with diabetes to play an active role during appointments and to passively follow the advice of healthcare professionals. The doctor’s decision to maintain insulin dosage instead of adjusting it to bring her blood sugar levels down is justified with reference to the potential extreme consequence of hypoglycaemia (160-161), constructing the doctor’s decision as sensible. This addresses the idea that changing the dosage might have been the expected response to the problem of high blood sugar that she has raised with the doctor. Hayley positions the doctor as the decision-maker (‘he doesn’t want to increase it again’) and Hayley’s role was to raise the problem and listen to the advice. Hayley does not imply any criticism for her lack of involvement in the decision or question the decision. The dilemmatic positionings of ‘patients’ as active and passive were managed by positioning people with diabetes and learning disabilities as active in specific contexts (to communicate information to the doctor but to follow the advice of healthcare professionals concerning medication). People with learning disabilities tended to position themselves as active when describing communicating with healthcare professionals (sharing their experiential knowledge) but as passive or compliant in decision-making around medication. This draws on ideas around the respective types of knowledge held by the patient and professional (discussed further in chapters 5 and 6).

More rarely, participants acknowledged the passive role but constructed themselves as rebelling against it. Lynne also positioned professionals in an instructing role but she did not position herself as compliant.
Extract 12

885  Interviewer:  What's the dietician like?
886  Lynne:  Not too bad.
887  Interviewer:  Not too bad. Is it easy to understand what she’s saying?
888  Lynne:  Yeah they say the same and I don't do it.
889  Interviewer:  They're saying don't do it.
890  Lynne:  Me
891  Interviewer:  Right yes, oh I see.
892  Lynne:  I don’t care so huh.
893  Interviewer:  Oh I see yes. So is it quite difficult to follow the advice you get?
894  Lynne:  Yes, yes that’s right.

(Lynne, line 885-894)

Lynne positions herself as rebellious, she makes it clear that she understands what the dietician says (the ‘same things’ everyone says) but chooses not to do it. Lynne emphasises that she is speaking about herself when the interviewer mishears ‘me’, ‘I don’t care so huh’. This contrasts with the examples above where participants are told what to do by the doctor and do what they are told. Lynne positions herself as competent, she understands and remembers what has been said ‘they say the same’ but chooses not to comply.

Therefore, people with learning disabilities sometimes constructed a passive role for themselves with professionals instructing and themselves following the advice. This contrasts with the proactive roles described earlier, that it is important to have involvement and take an active part in appointments. Participants were sometimes accepting of the passive role, particularly in relation to medication – following advice from professionals in this case is part of the ‘patient’ role. But they sometimes positioned themselves as rebellious.
4.2.2 Constructing the role of practice staff and healthcare professionals

People with learning disabilities constructed practice staff/systems and healthcare professionals as having a role to play in ensuring their diabetes appointments went well. The quality of diabetes care appointments was sometimes constructed according to whether practice staff and healthcare professionals fulfilled their responsibilities to ensure that the appointment process was an efficient and straightforward experience.

4.2.2.1 Flawed practice systems/staff

People with learning disabilities drew on interpretative repertoires relating to the role of general practice systems and staff when constructing the quality of diabetes appointments. This included the idea that for the appointment process to run smoothly, practices and professionals should fulfil their roles and responsibilities. Participants described practice systems and staff as flawed for not fulfilling their responsibilities, such as making convenient appointments and providing accessible information.

Thomas constructed his local surgery as flawed in comparison to his hospital for not providing easy read letters.

**Extract 13**

530  **Thomas:**  ... like the doctors they only use the small print where the – my - the hospital will always do it in basic print but with an easy read version for myself.
531  **Interviewer:**  That’s it
532  **Thomas:**  I I think and I put this as polite as I can, most places like hospitals, doctors and other places where you have to go for treatment
533  **Interviewer:**  Yes yes
534  **Thomas:**  should do an easy read version
535
536
537  **Interviewer:**  (Thomas, line 530-537)
The GP practice is constructed as inflexible/unhelpful in comparison to the hospital which is flexible and makes the effort to provide accessible information. Thomas uses contrast structures (Potter, 1996; Potter & Wetherell, 1987) comparing the good practice of his hospital ‘the hospital will always do it in basic print but with an easy read version for myself’ but with his GP surgery ‘the doctors they only use the small print’. Thomas moves from speaking about his own specific experiences to general health care facilities, all ‘places where you have to go for treatment’. Practices are therefore positioned as responsible for providing easy read as standard, his practice does not fulfil this role because they use small print and do not include an easy read version.

Below, William describes his hospital system as flawed in not sorting out delays (this refers to an experience of secondary care).

**Extract 14**

22 Interviewer: Oh so that's why you were waiting two hours?

23 William: Yeah two hours and thinking I was getting a little bit fed up and I wanted something to eat and things like that.

25 Interviewer: Yeah yeah. Did they come and tell you what was happening?

26 William: I er hhh well I don't - it took them about three to keep coming back to the receptionist to say 'William is getting anxious, he wants his dinner' and things like that.

29 Interviewer: Was that someone who was with you to=

30 William: =Yeah it was Simon my community nurse and the thing is that's (pause) they shouldn't do things like that they, should tell me straight away and my and my - and Simon too those things should be sorted all out.

(William, line 22-33)

William builds the case that being kept waiting is difficult, he gets fed up and needs something to eat, corroborated by reporting the speech of his community nurse. There is an implication that delaying mealtimes for diabetes is a problem. The receptionist is positioned as failing in their responsibility to keep William and his supporter informed and in keeping them waiting. Since he has not been kept informed, William positions himself as dependent on his community nurse to check and communicate with the receptionist.
Although not made explicit, it is possible that references to ‘getting anxious’ and needing to be kept informed relate to a need due to William’s learning disability.

4.2.2.2 Fallible healthcare professionals

Four participants regularly drew on the interpretative repertoire that healthcare professionals are fallible since they do not fulfil their roles.

This sometimes involved constructing health care professionals as fallible in that they may be unintentionally neglectful or remiss.

Extract 15

700 Interviewer: How do you find talking to the nurse?
701 Sue: They’re some- sometimes okay (.) but (.) it’s whether they listen or not (saying thinking what)
702 Interviewer: Right. Do they sometimes not listen?
703 Sue: They’re always usually in a rush ain’t they?
704 Interviewer: Yes
705 Sue: and they just don’t give you long enough to (.) talk about things
706 (laughs) which is annoying but I’m normally pretty good with them.

(Sue, line 700-707)

Sue starts by stating that nurses are ‘sometimes okay’ but immediately questions their quality by raising a possible flaw: ‘it’s whether they listen’. Responsibility for poor communication is positioned with nurses who may not listen, they are ‘in a rush’ and ‘just don’t give you long enough’. There appears to be some reluctance to make a strong criticism with the unclear end at line 702 and clarifying that ‘they’re always usually in a rush’ (704) which could be seen both as explanation and complaint. Use of ‘usually’ and ‘always’ emphasise that this is a regular occurrence. Instead of an excuse as identified in previous research on the social construction of quality appointments (Nagington et al., 2013a), busyness constructs nurses as at fault here (706-707). Not giving long enough implies that it is in their power to give you more time rather than there being a reasonable justification. Sue ends by positioning herself as competent to deal with nurses despite
having constructed communication with them as rushed and ‘annoying’: ‘I’m normally pretty good with them.’ This avoids questioning of her competence to communicate with nurses. It also constructs communicating with professionals as a task that requires skill, something that she is good at.

At other times professionals were constructed as fallible by describing experiences in which specific healthcare professionals had made mistakes.

Extract 16

120 Interviewer: So do you have your reviews at the hospitals or the GPs?

121 Thomas: The hospital’s told me not to have the reviews at the doctors because the reason why one nurse wanted to swap all my insulins over, take me completely off them in one in one twenty-four hours and then place me on another.

125 Interviewer: Right that was the nurse at the GPs?

126 Thomas: Yeah and you have you have to take, how it’s been told by me by the consultant, you have to allow at least a seven day window to take you off your first one and put you onto the second one.

129 Interviewer: Right, yes yeah.

130 Thomas: Then my consultant at the hospital was not happy so he writ a letter and she and they told me never to see her again cause because I was getting told I had to go on this old insulin what um going back a few year when I was still at school and it didn’t work and that’s why he told me not to sort of go back to see em because really I thought she should’ve read that in the information but she were too busy (.) making plans what she wanted to do instead of reading it.

(Thomas, line 120-137)

Thomas constructs his nurse as incompetent. Thomas brings in the authority of the hospital consultant several times to add supportive consensus to his judgement that the
nurse’s actions were wrong and serious. This account also builds a strong justification for not going to the GP surgery for reviews.

Thomas builds a case that the nurse’s actions were potentially dangerous and pointless; she wanted to replace all his medications without following procedure: ‘you have to allow at least a seven day window’, the medication had been tried before and did not work. Thomas positions himself as more knowledgeable than the nurse. He is knowledgeable about his own medication history and about how medications should be changed (based on expert information from his consultant). Thomas also gives it as his own view that the nurse lacks competence and is careless ‘I thought she should’ve read that in the information but she were too busy making plans’. The fault is placed specifically with the nurse by the hospital who told him never to see her again. The nurse is positioned as at fault and incompetent, she did not do what you should when changing medication and did not take notice of his history which would show this insulin had already been tried. The nurse’s advice was therefore incompetent because it would not have benefitted Thomas and may have been harmful.

4.2.3 The role of supporters

When describing the role that supportive others (e.g. paid or family carers) played in their appointments and their impact on the appointment experience, people with learning disabilities drew on three distinct repertoires, with different implications for the construction of quality.

- Support is essential and so the presence of a supporter enhances the experience but an appointment process that does not allow for support is of questionable quality.
- Support is needed as back-up only, it is helpful to have someone there in case you need them and for particular problems, but it is not essential.
- Support is unnecessary and either has no bearing on how quality is assessed or is a hindrance and prevents the person with learning disabilities from fulfilling their proactive independent role, therefore contributing to a poorer experience.
4.2.3.1 Support as essential

Seven participants sometimes drew on the repertoire that support in relation to diabetes appointments was essential since at least some elements of appointments would be difficult if not impossible alone. For some participants, the idea of arranging and attending an appointment without support could not be considered. Support was essential for two main reasons – i) the person with learning disabilities positioned themselves as lacking competence to manage alone and supporters as more competent, and ii) flaws in the appointment system or with specific staff/professionals make support necessary.

Support was described as essential in relation to a range of tasks before, during and after diabetes appointments, including: making appointments, knowing and remembering appointment dates, travel, listening to and understanding healthcare professionals, communicating with healthcare professionals, recording/explaining what was said during appointments and putting advice into practice. However, the repertoire of support as essential was most commonly drawn on when discussing communication with healthcare professionals during appointments.

One way in which participants described support as essential was by positioning themselves as lacking competence and so dependent on more competent others. For example, David explained why staff go with him to appointments.

Extract 17

252  **Interviewer:** Yes yeah so does someone who goes with you, do they help you to ask questions?
253
254  **David:** They do yeah.
255  **Interviewer:** Yeah. How do they help?
256  **David:** They would um (.) they would probably take me round there and then (.) keep it in their head what it all was  [and then]
257  **Interviewer:** [Oh yeah yeah]
258
259  **David:** come back here and all write it down again and they’d tell – that’s what they do all wri- writing everyday now and again.
260
(David, line 252-260)

555  **David:** ...I don’t like going in there on me own you see.
David positions himself as lacking the competence to get to appointments independently and to remember what was said, staff ‘take me round there’ and ‘keep it in their head’. Staff are implicitly positioned as more competent at and having the role of getting him to the appointment remembering and recording any information.

Framing going alone as something he dislikes, suggests a preference rather than a need ‘I don’t like going in there on my own’. This need is then upgraded to ‘I’ve got to have someone with me’, it is essential for him to have someone with him, positioning himself as lacking in cognitive competence and others (staff) as more competent to understand and support him to do so.

Within this repertoire people with learning disabilities were positioned as wholly or partially dependent on support to attend and/or experience successful appointments. When support was constructed as essential, accounts of failings in support arrangements drew on positionings of people with learning disabilities as helpless.

Like David, William positions himself as dependent on support. Unlike other participants who described support as coming mainly from staff or family, William positions friends and advocates as having a supporting role. William also positions himself as dependent on support during appointments, to the extent that difficulty arranging support may lead to appointments being cancelled.

Extract 18

59  William: And I feel very hhh n - my my staff at ((supported living
60  environment)) they only look after my care they don’t look after
61  hospital visits or anything.

62  Interviewer: Okay right

63  William: And that’s very tricky to get someone to to take me to hospital and
64  things it must be only Simon (Community Nurse) or Hannah but
65  Hannah is in case Simon doesn’t go on holiday Hannah is there as a
deputy and things like that.
William constructs support as essential but difficult ‘and it’s very tricky to get someone to take me on the day and sometimes we have to cancel these appointments and I’ve been told not to cancel these appointments, I’ve been warned cancel a visit that’ll take a long time to get another visit.

(William, lines 59-82)

William constructs support as essential but difficult ‘and it’s very tricky to get someone to take me’.

Support relating to diabetes (or any kind of appointment) is constructed as beyond the role of care staff in his supported living environment ‘they only look after my care’. This support is constructed as the role of the community nurse and his deputy, it ‘must be only’ them. William positions himself as dependent on this support, since not being able to arrange support has led to cancellations despite being ‘warned’ of the difficulty of timely rearrangement of the appointment. Arranging appointments is constructed as difficult and complex (a repertoire discussed further in section 4.3).

4.2.3.2 Support as back-up

Within this repertoire people with learning disabilities position themselves as largely independent with others sometimes playing a supporting role - supporters provide back up in case of difficulty.

Extract 19

Interviewer: ... How easy then do you find it if you want to ask questions during an appointment?

Sue: If I want to ask a question I usually just say (laughs), I’ve learnt to speak up for myself so so I’m normally pretty good at speaking up and if I can’t say it then Matthew my husband will step in and say it.
Interviewer: Yes. Right. So does he have an idea of things you might want to ask?

Sue: Yeah occasionally.

(Sue, line 797-804)

Sue starts by positioning herself as proactive, confident and competent to ask questions ‘*I will usually just say*.’ She has learnt to speak up for herself and is ‘*normally pretty good at speaking up*.’ It is usual that she will be able to speak for herself but her husband will ‘*step in and say it*’ if she has any difficulty communicating with professionals. This constructs the need for support as unusual for Sue. Her husband is therefore positioned in a supporting back-up role for the times that she cannot say it herself, but she is ‘*usually*’ ‘*normally*’ able to do this herself. Therefore, Sue positions herself as mainly competent and rarely dependent on support. Sue’s description of speaking up as something she is good at and has learnt to do constructs communication with professionals as a skill (which she usually has).

4.2.3.3 Support as unnecessary

Despite describing support as wholly or partly necessary, seven participants also drew on the repertoire that support is unnecessary, though this idea was drawn on less often than the idea that support is essential. Within this repertoire participants positioned themselves as independent and competent. Others can for example, go to the appointment with them if they want but this has no impact on the quality of their experience.

Sometimes support is present but does not help or hinder the participant.

Extract 20

310 Interviewer: Yeah. Do you go there on your own or do you have someone go with you?
311 Melanie: In the past I’ve gone with someone but lately I’m going on my own.
313 Interviewer: How did it help when you had someone with you?
314 Melanie: It was better. Well when I had someone with me it didn’t make much difference.
Interviewer: Right. What did they do when they came with you?

Melanie: Sort of sat there and watched what happens.

Interviewer: Oh okay. So they weren’t – they couldn’t give you much support?

Melanie: No

(Melanie, line 310-319)

Melanie constructs support as something that changes and evolves and though she has had support in the past she is currently independent ‘lately I’m going on my own’. Initially, Melanie describes having support in the past as ‘better’ but quickly downgrades the value of this support to ‘it didn’t make much difference’. Supporters are positioned as redundant or unnecessary, emphasised by her description of their inactivity during appointments, they ‘sort of sat there and watched what happens’. Supporters were observers but did not take part. This construction of support as unnecessary, perhaps prevents any questioning of Melanie’s competence and independence.

4.2.3.4 Support as unwanted

Two participants (Lynne and William) constructed the purpose of support as both unnecessary and unwanted. In the extract below, William builds the case that one element of his support is unnecessary and a hindrance to his independence.

Extract 21

Interviewer: Are you involved in making the appointments?

William: No I ain’t.

Interviewer: No

William: Want to - they wouldn’t let me do that.

Interviewer: Right yes. So who is it who makes
William: ((Simon)) but I would I would like to make the decisions for myself if I had my diary in front of me I can say what day I’m working for ((advocacy group)) and things like that I would like to do it myself but I don’t know I don’t think ((supported living provider)) would be very keen on that.

Interviewer: Why is that?

William: I don’t know. Be a little bit bit thing

(interview interrupted)

William: I don’t think they’re very keen on - I don’t think - they think I’ll get in a muddle but I don’t think I’ll get in a muddle. If I don’t learn things for myself that’s how to get on with life and things like that.

Interviewer: Yeah of course. Do you think there is anything they could do to help you to be more independent?

William: I don’t even know that that is

Interviewer: No

William: I’d like to, well I can I can make the decisions cause I’m a ((job role)) at ((advocacy group)) so I can’t see why I can’t.

Interviewer: Yes

William: Do you understand what I’m saying?

(William, line 113-136)

Throughout this extract, William expresses his unhappiness and frustration with others taking over the task of making appointments, often emphasising the point he is making to the interviewer. William positions staff as overbearing and controlling, they do not support but take over this task: ‘I would like to make the decision for myself’, ‘they wouldn’t let me’, ‘I don’t think they’re very keen’. William builds a strong case that this is against his wishes, repeating that he would like to do this himself (line 118,120, 133). He also builds a strong case that he would be capable, positioning himself as competent by describing how he would do it ‘if I had my diary in front of me’ and comparing the skills needed for this task to those he demonstrates in his responsible role for an advocacy group (133-134). William describes and strongly resists the incompetent positioning of him by others who think he will ‘get in a muddle’. Taking the opportunity to make decisions away from him is
constructed as wrong and unreasonable, since he has built the case that he is capable of
decision-making and decision-making and independence are presented as desirable ‘that’s
how to get on with life’. William positions himself as reasonable and wronged whereas those supporting him are positioned as unreasonable. This contrasts with the repertoire of support as essential, which William drew on in extract 18, where he positioned himself as dependent on the support of more competent others for his appointments to go ahead. In this example, by foregrounding positions of competence (133-134), William questions his dependence on support staff and draws on the idea that independence is important to the quality of his experience. This demonstrates an ideological dilemma (Billig et al., 1988) present in the talk of people with learning disabilities on the roles of supporters.

William positions himself as lacking the choice/power to make this decision, but his level of involvement is controlled by others who have an inaccurate view of his abilities. This reflects previous discussion of independence and empowerment as loaned by professionals/support staff to people with learning disabilities (Dowson, 1997) and guided by staff views/agendas (Antaki, Finlay, Walton, & Pate, 2008; Fullana et al., 2019). William is unable to change this situation: ‘I don’t even know that that is’. He draws on wider discourses around the importance of promoting independence for people with learning disabilities and perhaps suggests that the role of supporters is to enable independence and involvement in the appointment process.

Summary of 4.2

One way in which participants with learning disabilities constructed the quality of their appointment was to draw on repertoires relating to stakeholders having roles and responsibilities that they are expected to fulfil. This included constructing themselves as having a role in making appointments worthwhile by playing an active part in communicating with professionals or passively complying with their advice. Practice staff and professionals have a role to ensure the appointment process runs smoothly and that appointments are effective. The role of supporters and their contribution to the quality of appointments was constructed in varying ways, from essential (contributing to a positive experience), back-up (having some impact) to unnecessary (having no impact or questioning the quality of appointments). Key stakeholders fulfilling their expected roles (e.g. patients playing an active part in communication and effective healthcare professionals) contributed to the construction of positive experiences. Accounts of
stakeholders failing to fulfil their expected roles and responsibilities were drawn on to build complaints about the quality of appointments. People with learning disabilities sometimes drew on dilemmatic positionings of themselves which constructed different roles and responsibilities for themselves and their supporters. Conflicting ideas of the person with learning disabilities as having active and passive roles during appointments were managed by positioning themselves as active in relation to specific tasks such as communication but in a more passive role when describing decision-making, possibly drawing on repertoires of knowledge. Dilemmatic repertoires were also drawn on in relation to the roles and responsibilities of supporters. When people with learning disabilities positioned themselves as lacking competence and therefore dependent, supporters were constructed as essential to quality care. However, when the person positioned themselves as competent and thus capable of independence, supporters were constructed as unnecessary or a hindrance and examples of support which did not respect the individual’s desire/ability to be independent were described to question the quality of the experience.

4.3 Repertoires of difficulty

People with learning disabilities constructed their experience of appointments as on varying levels of difficulty including inconvenient, worrying/upsetting or straightforward and routine. In drawing on repertoires of difficulty to construct the quality of their appointments, participants with learning disabilities often drew on repertoires of reasonableness.

4.3.1 Diabetes appointments as difficult

Participants with learning disabilities often constructed diabetes appointments as difficult, for example, they are upsetting, worrying or nerve-wracking and inconvenient. These difficulties were constructed either as understandable and so accepted or unreasonable and so a cause for complaint.
4.3.1.1 Difficulties as unreasonable

Five participants described difficulties, inconveniences or unpleasant experiences relating to their diabetes appointments as avoidable and due to unreasonable/flawed systems and inflexible or deliberately obstructive people. They drew on the interpretative repertoire that professionals and healthcare systems can be unreasonable and that avoidable difficulties are cause for complaint. Repertoires of unreasonableness were usually drawn on to describe difficulties in making convenient appointments, long waiting times and difficult/unsatisfactory interactions with healthcare professionals and other practice staff. As discussed in section 4.2, this repertoire draws on the idea that practices/professionals have certain roles and responsibilities that are not being fulfilled.

Examples of things that are unreasonable are sometimes described as an exception to the rule, so may construct the specific experience as poor but not the overall quality of their appointments.

Participants drawing on this repertoire often described the problems as avoidable, sometimes with suggestions for how difficulties could have been avoided. In the extract below, Thomas constructs a difficult experience with a receptionist at his GP practice as avoidable.

Extract 22

887 Thomas: Well I sat at the GP surgery and I sat there for nearly two hours but
888 I didn’t go after ten minutes cause my mum was with me this time
889 and then the what they call the manager of the receptionist bit she
890 come out, she goes ‘we gotta’ she said ‘we’re closing now’ and she
891 said ‘what - have you got an appointment or do you need to be
892 seen?’ I said ‘no I said we give the receptionist my prescription, I
893 need an emergency one and she’s refusing to give me one for three
894 days’ then well twenty minutes after speaking to the manager side
895 of things she got me one printed off signed by a doctor cause my
896 practice has got a pharmacy downstairs
897 Interviewer: Oh right yes.
898 Thomas: they contacted the pharmacy electronically sent it by like a fax
899 whatever you call it then I went down and I got my stuff sorted
900 there and then.
Thomas constructs the receptionist at his practice as unreasonable by positioning her as deliberately and unnecessarily obstructive. This is done by giving an account of how easily his request was dealt with when it was carried out by someone else. Thomas positions himself as determined, he waits for the unreasonable amount of time it takes to speak to someone else and is supported to wait ‘I sat there for nearly two hours’. This presents the request as serious, he cannot leave until he has his prescription. It also positions Thomas as dependent on his mum in this situation.

The first receptionist’s decision not to give him a prescription is discredited in several ways. Thomas brings in the actions and speech of someone with more authority: ‘the manager of the receptionist bit’, describes her actions of dealing with his request efficiently and does not report any resistance (894-900). The manager has been able to quickly (twenty minutes instead of three days) give him what he asked for, demonstrating that this was possible. His reported speech of his description to the manager also constructs the receptionist as unreasonable and deliberately obstructive, constructing the situation as urgent ‘I need an emergency one and she’s refusing to give me one for three days’. Three days is clearly too long for something that is needed and an ‘emergency’, but the receptionist has ‘refused’.

Thomas positions himself as capable to solve the problem (with support). The receptionist is positioned as deliberately inflexible and obstructive by presenting Thomas’s need for the prescription as genuine and his request as simple to carry out (898-900) and her refusal to do so as a matter of choice (902).

4.3.1.2 Reasonable difficulties

Repertoires of reasonableness are mainly used to construct poor quality appointments but occasionally, for example in the case of long waiting times, they allow the speaker to describe negative experiences without evaluating the appointment as poor. Some difficulties with appointments are constructed as at least partially understandable if there
is a good explanation and the problem is unavoidable. The repertoire that some difficulties are understandable was drawn on by four participants.

Participants who constructed problems as reasonable often did so by drawing on the idea that if there is good reason for a problem, it is understandable and so not a cause for complaint. Below, Sue constructs appointment delays at her surgery as understandable.

Extract 23

331  Interviewer: How long do you tend to have to wait?
332  Sue: Not usually that long. Normally they’re pretty good at my doctor’s surgery unless they’re delayed for some emergency then it’s usually – half an hour’s the longest that I’ve waited.
335  Interviewer: Oh really?
336  Sue: Yeah cause they’ve had emergency in, which tends to happen (laughs) especially if they’re taking a blood press- a blood test and somebody passes out then=
339  Interviewer: =Oh I see, yes of course.
340  Sue: yeah so it is, it’s quite regular (laughter).
341  Interviewer: Yes, I can imagine. How are you with waiting?
342  Sue: I’m okay at waiting, I do get frustrated but they say ‘well they will be with you shortly’ ((changes to passive voice)) ‘oh okay’.
344  Interviewer: Does someone come and let you know if there’s a wait?
345  Sue: Yeah they do, the reception’s pretty good so.

(Sue, line 331-345)

Sue constructs the situation of delayed appointments as understandable and therefore not a cause for complaint. In fact, she twice describes her surgery as ‘pretty good’. She does this by initially describing long waits as unusual. As well as unusual, an extreme case is given to explain that delays only occur in an emergency ‘unless they’re delayed for some emergency ... somebody passes out’. She then shifts to constructing this as a fairly regular occurrence (336-340). However, this is still not cause for complaint (perhaps partly because it’s an emergency beyond the surgery’s control). Sue acknowledges that delays are frustrating ‘I do get frustrated’ this is tempered by the reasonableness of the surgery in
keeping her informed (342-343). Sue positions herself as understanding and reasonable. This is partly due to her character trait ‘I’m okay at waiting’.

Constructing potential difficulties as unproblematic therefore performed important identity work for participants, constructing them as reasonable in their understanding of the situation and competent to cope. Acknowledging that there is sometimes good reason for difficulties helped build the identity of the speaker as reasonable and understanding, which lends strength to any previous and subsequent complaints.

4.3.1.3 Difficulties due to disability

Although it was not a commonly used repertoire (perhaps because it does not construct a competent identity), six participants drew occasionally on the idea that disability (learning or physical) makes attending diabetes appointments difficult. This involved positioning themselves and/or others with disabilities as different and sometimes as requiring adjustments to appointments.

In the examples below, participants positioned themselves as disabled to construct their appointments as difficult.

Extract 24

572 Thomas: ... but the the problem is with appointments if my - if any the consultants or nurses and doctors whatever are running late I will not stop more than ten minutes after my appointment time

573 Interviewer: Oh right yes

574 Thomas: because it’s due to my disabilities if people are running late and they don’t tell me I’m gone home.

575 Interviewer: Mmm yes yeah.

576 Thomas: Or if I’m not gone home then I’m gone like somewhere just for a drink or whatever but it’s due to my disabilities that I’ve got poor time.

577

578

579

580

581

(Thomas, line 572-581)
Thomas positions himself as disabled to explain why he will only wait for a limited amount of time if there is a delay, referencing his disabilities twice: ‘it’s due to my disabilities if people are running late’, ‘it’s due to my disabilities that I’ve got poor time’. This draws on an ‘individual pathology’ discourse (Wilcox et al., 2006). Thomas constructs the situation in which this creates difficulties as specific ‘if people are running late and they don’t tell me’. This places some blame on the clinic staff who are responsible for letting him know. He also downgrades the consequences from going home to going somewhere ‘just for a drink or whatever’ perhaps minimising the seriousness of these actions. Along with taking up a disabled position, this defends against the potential impatient, unreasonable identity that his description of not waiting opens him up to. The use of minimisation and placing some responsibility with the professionals and others for not keeping him informed functions to avoid an entirely incompetent, stigmatised identity, something that is well documented in previous research on the talk of people with learning disabilities (Beart, Hardy, & Buchan, 2005; Finlay & Lyons, 2005; Jingree & Finlay, 2013; Rapley, 2004). Constructing difficulties as arising due to disability (thus internal) means they are not open to change on Thomas’s part whereas the external problems (delay and not being informed of delay) may be avoidable making some criticism of the appointment process.

In contrast, below Thomas constructs appointments at the hospital as easier than those with his surgery because they take account of the need created by his disability. It was rare for people to describe adjustments to their appointments due to disability.

**Extract 25**

<table>
<thead>
<tr>
<th>Line</th>
<th>1444</th>
<th>Thomas:</th>
<th>1445</th>
<th>Thomas:</th>
<th>1446</th>
<th>Thomas:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1447</td>
<td>Interviewer:</td>
<td>Well my appointments and things what’s helpful is like they work with myself with the times and not all hospitals or doctors or consultants or whatever will work with you.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1448</td>
<td>Thomas:</td>
<td>Like cause they know I don’t drive cause of my disabilities and other things and I have to get public transport and I think that’s a good reason they should work with you cause cause I could get the first appointment in the morning and not be there and I could get the last appointment in the evening what is about six o’ clock and not be there cause of my bus.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Thomas, line 1444-1453)
Thomas positions himself as disabled ‘I don’t drive cause of my disabilities’ but constructs the hospital as working with him to prevent his disability being a barrier to appointment attendance ‘what’s helpful is like they work with myself with the times’. They have a good knowledge of his disabilities and work with him to prevent the appointment being difficult to get to ‘they know I don’t drive cause of my disabilities and other things’.

Professionals are positioned as responsible to work with him (1448-1453) by building a strong account that this is necessary for him to get to appointments, including a theoretical scenario demonstrating how not working with him would be problematic (he might not make the appointment). However, he also positions his hospital/professionals as unusual in doing this (1444-1446). Thomas minimises the position of himself as disabled ‘cause of my disabilities and other things’. Describing professionals as ‘working with’ him constructs a much more equal balance of power than in the previous extract.

Two participants constructed disability as making appointments difficult by describing problems that theoretically others may face, whilst positioning themselves as comparatively competent.

Extract 26

991 Interviewer: What do you think makes an appointment good?
992 Sue: When they talk things through if you need to (.) which isn’t easy for somebody with a learning disability. Some of our members wouldn’t be able to do that so (.) having that other extra support there as well so you can talk things through.
996 Interviewer: So having like you have your husband there=
997 Sue: =or a carer or a parent or something yeah

(Sue, line 991-997)

Sue constructs what is good about an appointment (the opportunity to talk things through) as something that may be difficult for people with learning disabilities. Communication with professionals is important but possibly difficult due to learning disability. She positions others with learning disabilities as lacking the competence to effectively take part in this communication with others as responsible for providing them with support. Sue
makes it clear that she is not referring to herself but to ‘some of our members’ (members of an advocacy group) and clarifying that others may need a ‘carer or a parent or something’ (not husband which refers to herself).

4.3.2 Diabetes appointments as easy/unproblematic

4.3.2.1 Appointments as routine

In contrast to repertoires of diabetes care appointments and associated activities as difficult, participants often constructed their appointments generally or specific elements of their appointments as easy, routine and straightforward.

Participants constructed appointments and professionals as easy and straightforward or routine. This was a common repertoire drawn on by seven participants.

David constructs his appointments as straightforward.

Extract 27

223  Interviewer:          What’s the waiting area like at the doctors?
224  David:                It’s alright, it’s good. Don’t wait very long
225  Interviewer:          Yeah, oh that’s good.
226  David:                just go in there about a couple of minutes and then come out
227                      again.
228  Interviewer:          Really? Oh okay, that’s good. You’re not sitting around?
229  David:                It’s not, yeah it’s not long cause they ask you questions you know
230                      like ‘how are you getting on with yer diabetes?’.

(David, line 223-230)

David starts by describing the waiting area as ‘alright’ an example of ‘emotional blandness’ (Goble, 1999) which was then upgraded to ‘good’. The waiting area/appointment are constructed as good by referring to characteristics of the appointment system; waiting times and that the time spent in the appointment is brief. Three times David equates
speed with a good/easy appointment (224, 226, 229). The example of what happens during appointments also constructs appointments as easy (asking how you are getting on) and the moderating term ‘just go in’ minimise the seriousness of what happens during the appointment.

Sometimes participants constructed appointments as easy by describing them as routine or ‘normal’ rather than describing things that made them good. At times, as with Thomas this involved referring to their own involvement as well as the system or professionals.

Extract 28

1109 Interviewer: Yes. Is there anything you like about the way they do your eye checks?
1110 Thomas: I just take it as normal cause like I’m always (.) I’m always forward and that
1111 when they say to look at a certain line on the board for instance where the
1112 letters are then I’m always honest and like they they usually start from top to
1113 bottom then they like to change it for instance from bottom to top and say
1114 which one’s best to read and I always go line whatever and then they then
1115 they the doctor will consultant will tell me whether my be - like letter if it has
1116 got better or worse and he’ll always do his checks what he needs to do and he
1117 will always tell me if that’s better or worse.
1118 Interviewer: Yes is there anything you find difficult about the eye check?
1119 Thomas: No I - the eye check I I think is quite easy cause cause it’s not one of those
1120 things you’ve gotta wait ages for the results you can get them there and then.

(Thomas, line 1109-1120)

Thomas constructs his eye checks as routine and ordinary ‘I just take it as normal’. The detailed account of what happens during this check demonstrates his knowledge and memory and strengthens his account. Thomas constructs himself as competent to complete the check and play an active role. His role involves being honest with the professionals. Thomas constructs his role/positioning as consistent ‘I’m always forward’, ‘I’m always honest’. The professionals are positioned in an assessing and informing role. Thomas describes this check as easy since there is no wait for the results ‘I think it’s quite easy cause cause it’s not one of those things you’ve gotta wait ages for the results’. Like David, easy is constructed as quick.
People with learning disabilities drew on repertoires of reasonableness when describing difficulties relating to their appointments. Whether a difficulty was constructed as cause for complaint was dependent on whether the problem was constructed as reasonable or unreasonable and avoidable. Difficulties were sometimes accounted for using positionings of disability, with appointments that made adjustments to meet the individual’s needs constructed as easy.

Participants constructed appointments as unproblematic/routine through descriptions of efficient smooth and speedy systems, ordinariness and absence of difficulty. Minimising terms were used and there is some evidence of emotional blandness. Sometimes participants positioned themselves as having a role in making the appointment go smoothly.

4.4 Chapter summary

People with learning disabilities drew on multiple and sometimes conflicting ideas to construct the meaning of quality care. Quality care achieves the purposes of primary care diabetes appointments and involves stakeholders fulfilling their roles and responsibilities.

It is also dependent on whether the appointment process involves difficulties or is straightforward and routine. An interesting finding was that if the person presented coverage of a topic/care process as beyond the role of primary care appointments then failure to include them in the appointment was not used to question quality care. Within these repertoires, participants drew on varying and sometimes conflicting ideas and subject positions, producing ideological dilemmas (Billig et al., 1988). People with learning disabilities drew on some varying ideas around the purpose of diabetes primary care appointments to construct the quality of their care. This included passive and proactive positionings of people with learning disabilities. Supporters were positioned in three different roles: essential, back-up and unnecessary. All stakeholders were constructed as having roles and responsibilities and complaints of poor quality were supported by descriptions of failure by stakeholders (often primary care staff) to fulfil their responsibilities. To support different constructions of quality care, people with learning disabilities drew on conflicting and sometimes dilemmatic positionings of themselves and others. Positionings of competence were drawn on to question the quality of care that
hindered active involvement and independence of the person with learning disabilities, whilst positions of dependence contributed to constructions of quality care as dependent on assistance from more competent supporters. Thus, what constituted quality care depended on how the appointment purpose was constructed and how stakeholders were positioned in terms of their roles and responsibilities. Practice staff and professionals were positioned as responsible to ensure that the appointment process is unproblematic and effective. Difficulties presented as unreasonable and avoidable were drawn on to support accounts of poor care, but where difficulties were presented as justifiable quality of care remained unquestioned.

The ways in which people with learning disabilities constructed quality care in relation to their diabetes primary care appointments performed identity management. People with learning disabilities frequently privileged the identity of ‘diabetes patient’ (who needs to be informed, proactive, independent and self-managing) over the identity of ‘learning disability’ and sometimes actively resisted characteristics associated with the learning disability identity. In contrast, at times identities of disability and difference were foregrounded to make complaint about appointments which had not been adapted to take account of any different needs. This has implications for quality care provision. Quality care was equated with the achievement of appointment purpose. The goals of these appointment were flexibly constructed and not always in line with diabetes quality standards and guidelines.

Chapter 5 Findings ii) - The construction of quality diabetes primary care appointments by people who support adults with learning disabilities

This chapter focuses on the analysis of six separate interviews with people who support adults with mild-to-moderate learning disabilities in relation to their diabetes care appointments and the contributions of four of these supporters during interviews with the person they support. One supporter (Lucia) was unable to take part in a separate interview but her contributions to the interview with the person she supported were included in analysis (see methods chapter for details). All supporters provided appointment related
Supporters and participants with learning disabilities drew on some similar broad ideas to construct the quality of diabetes care appointments. These included: that diabetes care appointments have purposes that should be achieved and that all stakeholders have roles and responsibilities that should be fulfilled. However, there were some differences in the pervading interpretative repertoires and subject positions used to assess the quality of appointments. Specifically, supporters drew regularly on socially available ideas around the (in)dependence of people with learning disabilities and on constructions and positionings of this population as different to people without learning disabilities. They also drew on repertoires of knowledge to construct their professional identity and to question the effectiveness of the professional medical based knowledge of some healthcare professionals. This chapter therefore focuses on these key ideas and how they were used by supporters to build accounts of quality in the primary care diabetes appointments of the people they support. Since participants drew on conflicting repertoires to construct quality appointments, the ways in which these conflicting repertoires were used and managed is also considered. This chapter is organised according to 4 key repertoires: i) the purpose of appointments, ii) repertoires of knowledge, iii) roles and responsibilities and iv) independence and choice.

5.2 Constructing the purpose of appointments

In common with participants with learning disabilities, supporters drew on the idea that appointments have purposes and equated quality care with the achievement of appointment aims. Since supporters drew less often on these ideas than participants with
learning disabilities, due to limited space this chapter deals only briefly with this area before focusing on more prevalent repertoires. Supporter constructions of the goals of diabetes primary care differed from other stakeholders (see chapters 4 and 6) in terms of the absence of a concern with the successful completion of care processes, instead emphasising the need for appointments to be positive and motivating.

5.2.1 Appointments as positive and motivating

When constructing the quality of diabetes appointments participants drew on the repertoire that appointments should inform people with learning disabilities about their diabetes in a positive way that avoids frightening the person and motivates good or improved diabetes management. Five supporters constructed appointments as ‘good’ quality care through their achievement of this aim; they described professionals making the appointment an enjoyable, motivating experience for the person they support.

Peter is a former care manager and supported David who has type 2 diabetes and lives in a supported living environment. Below, Peter positions the GP as ‘good’ for her ‘relaxed’ approach.

**Extract 1**

221 Peter: because the GP’s very – she’s she’s quite relaxed about the whole thing you know she she tries to make it interesting for people and doesn’t you know if if you’re bloods are up a little bit she’s not gonna go ((changes to worried voice)) ‘oh my goodness me’ you know and put her head in her hands she’ll she’ll say like ((changes to calm voice)) ‘they’re up a little bit now how can we get that round? What do you have for breakfast? What do you have for lunch? What do you have for tea? What snacks do you have? Can we just get that back a little bit?’ She’s she’s very very nice you know and very very good with the guys, very good.

(Peter, line 221-230)

The GP is positioned as calm, sensible and practical in comparison to the theorised alternative extreme reaction. She does not respond to what is presented as a moderate
problem of blood sugars that ‘are up a little bit’ by despairing and ‘put her head in her hands’ (223-225) but looks for explanations and solutions (226-229). Peter acts out the GP’s calm approach and the theoretical more dramatic approach, changing his voice and reporting their speech in both cases. These are devices which strengthen stories (Seymour-Smith, Wetherell, & Phoenix, 2002) and add an evaluative account (Bakhtin, 1981, as cited in, Maybin, 2001). In this case, the more dramatic approach (224) is evaluated as unnecessary and unproductive in comparison to the calmer, more practical approach taken by the GP (226-230) (she looks for explanations and suggests solutions). Peter moves from talk of this approach for ‘people’ generally to praising the GP for being ‘very good’ with ‘the guys’ he supports specifically. There is an implication that this relaxed approach is particularly helpful for people with learning disabilities and that being ‘very good with the guys’ is a skill to be appreciated. This implicitly positions people with learning disabilities as different from other people with diabetes.

Alternative descriptions of experiences of diabetes appointments which were not positive or motivating were rare but can be seen in the example below from Karen. In this case the appointment was constructed as ineffective because it involves censure, which demotivated healthy behaviours and may reinforce existing unhealthy habits. Karen supports Pauline who has type 2 diabetes and lives in a supported living environment.

**Extract 2**

Karen: but she does have a good understanding of it but she also knows that (. ) with with her doctor he can be a bit of a no nonsense and
wags his finger at her and says ((changes to strict voice)) ‘if you carry on you you could be in serious like trouble and and you could be on insulin and worst of all you could die’

Interviewer: Right yes

Karen: and all of those sorts of things but with Pauline I don’t think that necessarily helps her. I think what would sort of guide her into eating better was if there was some sort of reward system

Interviewer: Right yes yeah
Karen: so if she knew that she’s eating really healthily and on her day
where she goes to the bank perhaps she gets she can pick up
something to say you know well done, you you really deserved it
and you did well because (.) then when she did try and eat well no
one was really giving her a pat on the back

Interviewer: Oh okay

Karen: they were like ‘well this is what you’re meant to be doing’ you
know

Interviewer: Right I see yes.

Karen: and she thought ‘well hhh don’t really want to do that any more I
may as well go back to (.) what I was enjoying’

(Karen, line 21-41)

Karen positions the doctor as a strict authority figure; she describes him as ‘no nonsense’
and wagging his finger and changes to a strict voice to report his speech (21-25). The
doctor’s reported speech emphasises the seriousness of Pauline’s poor diabetes
management, positions Pauline as responsible (‘if you carry on’). This approach is
presented as extreme by describing the use of an extreme case formulation (Pomerantz,
1986) ‘worst of all you could die’, to frighten Pauline into improved diabetes management.
In contrast, Karen presents the theoretical desired alternative to this approach, which
would ‘guide her into better eating’ through ‘reward’. Karen builds a case for this
rewarding approach, since it would particularly suit the individual she supports (27-29) who
needs motivation and incentive. Again, this may position the person with learning
disabilities as different from other people with diabetes in her needs for a motivating and
rewarding approach from professionals. In contrast, the ‘no nonsense’ approach taken by
the doctor is presented as unsuccessful, since it leads Pauline to go back to unhealthy
habits (40-41). This supports Karen’s positioning of the doctor as flawed in his approach
and constructs the appointment as of little value or counter-productive in the aim to
improve Pauline’s diabetes management. It also constructs Karen’s experiential knowledge
of the personality and preferences of the person she supports as more effective than the
doctor’s medical knowledge.
Karen goes on to describe how supporters compensate for the unsuccessful care of the GP by drawing on their knowledge of Pauline as a person to more successfully motivate improvements to her lifestyle.

**Extract 3**

Karen: ...we had to put it in a way where she has a really good social life, we said if you are insulin dependent and we can’t support you on a trip with ((name of leisure group)) then you can’t go so she did look at it that way and say ‘well I’ve I’ve got to change how I eat so I can carry on doing the things I like’ but there...

(Karen, line 50-54)

Unlike professionals who have tried to improve Pauline’s diet through fear and censure (she could go on insulin) staff have used their knowledge of Pauline’s life and preferences to put lifestyle change in terms that are meaningful to her. Contrasting reported thoughts from Pauline are reported to build accounts of staff intervention as successful in comparison to the GP (‘I may as well go back to what I was enjoying’ vs ‘I’ve got to change how I eat so I can carry on doing the things I like’). Strikingly, both the GP and supporters are described as employing a threat of serious potential consequences of Pauline’s lifestyle. With their nuanced knowledge of the individual, support workers are able to frame consequences in a way that is of significance to Pauline which results in success. A contrast can also be seen in the more extreme finger wagging approach of the doctor and the more reasoning approach of staff who put it to her. Pauline is presented as lacking the competence to come to this conclusion unaided.

The examples above demonstrate that supporters constructed effective or ineffective care through accounts of positive or negative encounters with healthcare professionals. Where supporters and the person they support were both interviewed, there was often agreement over what constitutes a positive encounter with healthcare professionals. For example, Hayley and her support worker Sally both described the ‘straightforward’ approach of healthcare professionals to communication as contributing to her positive experience. In the account of one pair of participants, contrasting constructions of the same experience as positive and negative can be seen. Lynne who has type 2 diabetes and Lucia who is her keyworker within a supported living environment discuss a recent
consultation with a new GP. This extract is taken from an interview with Lynne to which her supporter Lucia also contributed. Lucia has prompted Lynne’s memory by stating that the GP ‘was explaining to you the effect of ... diabetes in your organs’.

Extract 4

1209 Lynne: “It upset me a lot”
1210 Interviewer: Sorry?
1211 Lynne: hhhhh
1212 Interviewer: did you say it upset you?
1213 Lynne: A bit yes.
1214 Lucia: To be honest she ((doctor)) was also quite nice because Lynne she was trying to understand how you feel because for you it’s difficult to give up sugar and she was saying to her ‘I know it is difficult for you, maybe we can balance’ no? Obviously you’re not gonna have everything super super healthy you need some treats, not too much obviously no? she was she was really really understanding with you Lynne do you remember that when she was - and you really liked it.

(Lynne & Lucia, line 1209-1221)

Lynne states that the GP’s discussion of the potential complications of diabetes ‘upset me a lot’. This was said in a notably quieter voice and when the interviewer asks for clarification Lynne immediately downgrades her complaint from ‘a lot’ to ‘a bit’ (1209-1213), reminiscent of previous reports that people with learning disabilities tend to moderate claims of dissatisfaction and strong emotions (Goble, 1999; Jingree, 2009; Jingree & Finlay, 2011). Lynne’s support worker Lucia immediately questions the accuracy of Lynne’s account of her experience (‘to be honest’). Lucia then builds an account to support her alternative version of the appointment as a positive experience. The doctor’s reported speech adds evidence to her account (Wertsch, 2001) illustrating an understanding, non-censuring approach (1216-1217) similar to that described by Peter in extract 1. This draws on ideas around person-centred care as quality care since the doctor aims for diabetes care that will be realistic for Lynne ‘you’re not gonna have everything super super healthy you
need some treats’. Lucia attempts to prompt Lynne’s memory (1219-1220). Lucia’s statement at line 1220-1221 completely reframes Lynne’s description of the experience as upsetting ‘you really liked it’. In this way, Lucia again questions the accuracy of Lynne’s negative account of the experience (she may have forgotten how good the doctor was). Lucia does not question her own memory of the encounter or acknowledge Lynne’s alternative description of her experience. Although supporters constructed providing a positive experience as an important goal of diabetes care appointments, it is worth noting that there was sometimes mismatch in what constituted a positive experience by people with learning disabilities and people who supported them.

Summary of 5.2

In common with people with learning disabilities, supporters regularly constructed quality care according to whether the appointment achieved its aims. Specifically, supporters drew on the idea that a key purpose of diabetes primary care appointments for this population is to provide a positive experience which motivates or reinforces successful diabetes management. A positive experience requires good knowledge and understanding of the individual. Supporters sometimes positioned themselves as having superior knowledge of the individual they support and how to successfully support their diabetes management compared to healthcare professionals (discussed further in section 5.3). For all stakeholders quality care was equated with the achievement of appointment purposes but what the goals of these appointment are and what constitutes a positive experience was flexibly constructed and not always in line with each other.

5.3 Repertoires of knowledge

Supporters regularly drew on repertoires of knowledge to construct quality diabetes care. As highlighted in each section of this chapter, ideas about the nature of knowledge, types of knowledge, who knows best and the implications of knowledge for quality diabetes care were present throughout the interviews with supporters. Different stakeholders were constructed as having different types of knowledge which have different value when it comes to effective diabetes care. Types of knowledge included the medical knowledge of diabetes and its management, experiential knowledge of the person with diabetes and knowledge of people with learning disabilities and specific individuals gained through ‘on
the ground’ experience (their lifestyle, characteristics, physical and cognitive abilities and personal preferences). As seen in section 5.1, appointments were often constructed as effective or ineffective depending on the primary care practitioner’s level of experiential and contextual knowledge of the person with learning disabilities.

There were numerous references to knowledge relating to all stakeholders by supporters and indicated throughout this chapter. This section focuses in on a particularly prevalent repertoire of knowledge used by supporters to construct the quality of diabetes care: the distinction between medical knowledge of diabetes and experiential/contextual knowledge of the individual. Supporters tended to construct the value of experiential personal knowledge held by supporters as overriding the value of impersonal context-less medical knowledge when considering quality diabetes care.

5.3.1 Medical vs experiential knowledge of healthcare professionals

Healthcare professionals were positioned as medically knowledgeable and either entirely lacking in personal and contextual knowledge of people with learning disabilities/the individual or having a level of understanding of the person developed through continuity of care. This can be seen in the contrasting accounts of GPs who have or lack knowledge of the person with learning disabilities in section 5.1. Constructions of healthcare professionals who lacked knowledge of the person, built accounts of inadequate or poorer quality care which was demotivating, made incorrect assumptions and/or failed to appropriately adapt the appointment process, goal setting and advice to the individual.

Below, Peter describes a reduction in the quality of eye screening appointments following recent changes in provision for the people he supported.

**Extract 5**

675 Peter: ...with the diabetic eye screening now that it’s not the optician and
676 that’s n- for no other it’s not that the people aren’t good at what
677 they’re doing, that’s solely down to the fact that they don’t know
678 the person so it’s a bit of a production line
Peter makes a clear distinction between quality in terms of practical function/medical competence and quality in terms of adapting the appointment to people with learning disabilities/ the individual. The eye screening is successfully achieved but lack of knowledge of the individual/ people with learning disabilities makes the process ‘a bit of a production line’. The professionals at the new screening service are constructed as lacking knowledge of people with learning disabilities generally (they do not have learning disability training and do not know the individuals well) thus unaware of the value of adaptations to communication or giving more time (680-683). This is contrasted with the former optician’s long experience of the individual who was ‘very very good’. Peter implicitly presents himself as knowledgeable in contrast, he knows the types of adaptations that should be made for people with learning disabilities and is aware of and able to call out differences in the quality of their care.

5.3.2 The experiential professional/practical knowledge of supporters

References to this experiential learning disability/personal knowledge held by supporters were presented in accounts of effective care informed by supporter knowledge or to highlight inadequate care based on the more limited medical knowledge of healthcare professionals. In particular, care informed by learning disability/personal knowledge was drawn on in accounts of person-centred care whereas inadequate/unsuccessful care informed only by medical knowledge failed to tailor care to the individual.

In the extract below, Kamilla makes a clear distinction between the medical knowledge of healthcare professionals and the experiential knowledge of supporters.
Extract 6

395  Kamilla:  ...Obviously they’re health professionals and I’m not a doctor so I’m
396  not the one to decide but if they want us to do something with
397  Patrick and I know it will not work because he won’t be able to do
398  it then I will say that and then we will look for an alternative which
399  yeah they always do

400  Interviewer:  Yeah

401  Kamilla:  yes they know that Patrick has got a really good staff with him and
402  and they know we know him very well so if we actually point our
403  concerns or it’s like ‘that doesn’t gonna work we need to do
404  something else’ then they will try to look into some some
405  alternative so.

(Kamilla, line 395-405)

Kamilla initially acknowledges the knowledge of healthcare professionals as a basis of
decisions about Patrick’s diabetes care ‘I’m not the one to decide’. This distinguishes the
professional role of healthcare professionals from the professional role of herself as a
support worker. Employing this show concession (Antaki & Wetherell, 1999) positions
Kamilla as reasonable (she knows healthcare professionals have superior diabetes
knowledge) which strengthens her subsequent account of the value of her own type of
knowledge. Kamilla then builds an argument for her/supporter knowledge of the individual
which allows supporters to judge whether the healthcare professional’s advice will work in
practice (‘I know it will not work, ‘he won’t be able to do it’ and supporters know Patrick
‘very well’). The views and actions of the healthcare professionals are brought in to give
supportive consensus to the validity of Patrick’s supporters’ experiential knowledge. The
decision-making professionals know that Patrick’s supporters know him well and thus listen
to and act on their advice (401-404). Three references are made to finding an alternative
(‘we need to do something else’) and it is made clear that supporters will intervene if they
know what the healthcare professional ‘wants’ will not work. This demonstrates
Kamilla’s/supporters’ willingness to put healthcare professional advice into practice if it is
achievable for the individual, defending against the potential interpretation that
she/supporters are being obstructive. Throughout this extract, Patrick is positioned in a
passive role (the possibility of Patrick agreeing a compromise with professionals is not
Supporters are positioned in an advocating role, using their own experiential knowledge of the individual and his limitations to negotiate realistic goals with healthcare professionals on Patrick’s behalf.

Summary of 5.3

Supporters distinguished between different types of knowledge which play different roles in the quality of diabetes care. Supporters have professional knowledge of people with learning disabilities and experiential knowledge of the individual and the context in which they manage their diabetes. This experiential personal and contextual knowledge was often constructed as superior to the medical diabetes knowledge held by healthcare professionals and the reliability of the reported knowledge of the person they support in terms of improving diabetes care/the outcome of appointments. Professionals who lacked understanding of the person were referenced to build accounts of inadequate care. Their approach was posited as less likely to enhance diabetes care in practice in comparison to supporters whose knowledge of the person was more often presented as successfully informing lifestyle changes. Although supporters acknowledged the medical knowledge of healthcare professionals, their own knowledge of the person was constructed as vital to ensuring effective diabetes appointments and realistic person-centred care.

5.4 Roles and responsibilities

In common with participants with learning disabilities, participants who were supporters drew on the idea that stakeholders have certain roles and responsibilities and assessed the quality of appointments according to whether these were fulfilled. For participants who were supporters, the key roles and responsibilities arose from overarching interpretative repertoires and positionings relating to people with learning disabilities. These were: i) people with learning disabilities should have involvement, independence and choice in relation to their diabetes appointments; ii) people with learning disabilities are different to other people so have different needs from their diabetes appointments. Appointment quality was therefore judged according to whether supporters and healthcare systems fulfil their responsibilities to i) promote involvement, independence and choice relating to
appointments and ii) provide support and adjustments to accommodate the different needs of people with learning disabilities.

5.4.1  People with learning disabilities as patients – it is their appointment

As described in chapter 4, people with learning disabilities often drew on the idea that it was important for them to actively participate in their appointments to ensure a positive experience and positioned themselves as responsible for playing a proactive role. Similarly, supporters drew on the idea that it is important for the person they support to be involved and proactive in their diabetes appointments but placed the onus on healthcare professionals and themselves to ensure that the people they support played an active role in their appointments.

One idea commonly employed to construct the role of the person with learning disabilities was that the person is the ‘diabetes patient’.

The interpretative repertoire that the person with learning disabilities is the patient and as such should be the focus of the appointment was drawn on in all interviews with supporters. Four supporters praised healthcare professionals within diabetes care appointments for talking to the individual instead of the supporter, making comparisons to their different experiences in other areas of healthcare. In the extract below, Sally explains that the focus of communication during appointments is not and should not be staff members. Sally is a member of staff at a supported living environment and key-worker to Hayley who has type 1 diabetes.

Extract 7

182 Interviewer: How well do they communicate with you do you think?
183 Sally: Um (pause) I think that they don’t like I said earlier they don’t offer...
184 ... they talk to Hayley they and because it is her appointment
185 we’re there to support her but they unless we specifically ask they
186 won’t um kind of look at us and go ‘oh and she needs’ — they won’t
187 talk like she’s not in the room they’ll always talk to Hayley which I
188 which I really admire I think that’s great cause that doesn’t always
happen erm but they will if we ask questions then they will communicate with us brilliantly

Interviewer: Yes yeah. Oh that’s good.

Sally: but they won’t offer us information and not Hayley they’ll always talk to Hayley first.

(Sally, line 182-193)

The question at line 182 assumes a need for professionals to communicate with staff during appointments, an idea that Sally immediately questions (183-185). In her description of the approach taken by healthcare professionals, Sally presents professionals positioning Hayley as the patient; professionals always talk to her first and will only communicate with staff if they ask a question. Sally also positions Hayley as the patient, making a clear distinction between Hayley’s role (emphasising the word ‘her’) and the role of staff (184) ‘it is her appointment we’re there to support her’. Making use of contrast structures (Potter & Wetherell, 1987), the account of professionals treating Hayley as the primary focus of appointments is constructed as right and admirable compared with the theoretical behaviour of ignoring her (186-188) and with a brief reference to other experiences ‘that doesn’t always happen’ (188-189). The professionals in Hayley’s diabetes appointments are consistent in their prioritising of her as the patient ‘they’ll always talk to Hayley’. At the end of this extract the possibility is raised that professionals may need to talk to staff since ‘they’ll always talk to Hayley first’.

Two supporters (Karen and Jennifer) described instances of professionals focusing on themselves instead of the individual during diabetes appointments and assessed this as poor in comparison to the behaviour of professionals who aim their talk at the individual.

Extract 8

Karen: Quite often to tell you the truth they don’t really talk to her they tend to talk to us so she’s sort of forgotten really

Interviewer: Oh I see yes

Karen: but like again it it depends who you see. Some people are quite person-centred and they will talk to Pauline and they do sort of every so often if you if she doesn’t want to answer something and
you attempt to answer for her they’ll say ‘hang on a minute like
Pauline needs to answer’ and then you think ‘ooh yeah I should
really be quiet’ but yeah and then others they they don’t even
bother trying to talk to her first they will go straight to you so yeah
(.) it just depends who you see

(Karen, line 257-267)

Not focusing on the individual is presented as a difficult/unacceptable truth ‘quite often to
tell you the truth’. Some professionals are described positioning Pauline as having no role
in her own appointment and this is not unusual but ‘quite often’. Karen contrasts the
‘person-centred’ approach of professionals who focus communication on Pauline with
those who communicate only with staff, leading Pauline to be ‘forgotten’. Referencing the
idea of person-centred care positions Karen as knowledgeable about the responsibilities of
healthcare professionals and able to identify whether or not these have been met.
Reported speech is used to strengthen her construction of person-centred professionals as
good, demonstrating their prioritising of Pauline to the extent that they may remind staff
(262-265). As above, this distinguishes between the role of the person with learning
disabilities who is the patient and the role of staff who should support but not take over.
Karen also raises the possibility that staff input may be needed since professionals are
criticised for going straight to staff without ‘trying’, raising the possibility that staff could
and should have some input. Healthcare professionals are positioned as inconsistent in
whether they view the person with learning disabilities as the patient or foreground her
identity as a person with learning disabilities by speaking to her supporters ‘it just depends
who you see’. This may also be forgotten by supporters (262-264). Whether the position
of patient is available to people with learning disabilities depends on whether professionals
make an effort or ‘don’t even bother’ and whether staff remember, again constructing the
role of proactive patient as open to question for this population.

5.4.2 Responsibility to adapt appointments to the competency of the individual

In contrast to the discussion above, where supporters positioned the person with learning
disabilities in terms of their similarities to other people with diabetes, supporters also often
positioned the person they support and/or people with learning disabilities generally as
different to people with diabetes who do not have learning disabilities. Participants
regularly drew on the idea that people with learning disabilities have different levels of
cognitive, social and emotional competence to people without learning disabilities and that
their appointments should be adapted to accommodate these. This repertoire was often
used when describing communication. Appointment quality was therefore regularly
assessed according to whether practice staff and professionals tailored their
communication style to the needs of the individual. For example, by simplifying
information or making use of visual aids.

In the example below, Peter, distinguishes between the communication styles and needs of
people with and without learning disabilities during diabetes appointments.

Extract 9

1143  Peter:  ... if you or I went to an appointment the doctor is gonna speak to
1144    us in exactly the same way. If you took five people with a learning
1145    disability (.) that doctor’s got to speak to them probably in five
different ways

1147  Interviewer:  Yes yeah

1148  Peter:  to to help them to understand that’s why continuity is incredibly
1149    important in my opinion and that (.) that doctor’s gotta if they
1150    haven’t got that continuity they’ve gotta make an assessment at
1151    the time on a twenty minute appointment on how they’re gonna
1152    communicate with that person so before they do anything they’ve
1153    gotta learn how to communicate with that person

1154  Interviewer:  Mmmm

1155  Peter:  you know with with us they’d just read off all the stuff and hope
1156    we understand the the technical jargon but so like I say the
1157    continuity is incredibly important...

(Peter, line 1143-1157)

Contrast structures and categorisations (Potter & Wetherell, 1987; Potter, 1996) are used
to present people with learning disabilities as lacking cognitive competence and having
different communication needs in comparison to people without learning disabilities.
Communicating successfully with each individual with learning disabilities is described as
something the doctor has to learn on the spot or through prior experience (1148-1153). This constructs people with learning disabilities as a heterogenous population, with varying levels of cognitive competence. The doctor could speak to different people without learning disabilities ‘you and I’ in the same way but might need to find a different way to speak to each different person with learning disabilities so that they understand. This is in contrast to people without learning disabilities who are positioned as a group who are likely to understand. Lack of competence is associated with disability and so not open to change. Professionals are consequently positioned as responsible for adapting communication to each individual with learning disabilities ‘to help them to understand’ whereas if they are speaking to someone without learning disabilities (1155-1156) the doctor can ‘hope we understand’. This constructs working with people with learning disabilities as challenging for healthcare professionals and people without learning disabilities as comparatively simple to work with. Peter also builds a case that appointments are successful when there is continuity so that the professional knows the individual’s level of understanding and can tailor their communication accordingly. People with learning disabilities are again different since for their appointments to go well ‘continuity is incredibly important’.

Positionings of people with learning disabilities as lacking the cognitive competence to understand also led supporters to construct a positive appointment process as one in which information was simplified either by supporters, professionals or the practice. In the example below, Sally constructs healthcare professionals as ‘good’ for simplifying their explanation of test results to suit the comprehension abilities of the person she supports.

**Extract 10**

190 Sally: ...rather than going ‘oh your level is this’ they’ll say ‘well um yeah it all looks good it all looks fine’ um and yeah it’s straight talking or if
191 if she has had some hypos they might directly ask her (.) they’ll
192 they’ll find a way to ask her you know especially someone whose
193 seen her a few times they’ll know they’ll know how to um how to
194 get that kind of information um maybe ask in a slightly different
195 way if they don’t get it the first time.
196

(Sally, line 190-196)
Hayley is positioned as different through her need for adapted communication that avoids details and in that health care professionals need to find the right way to ask her questions to get the information that they need (192-196). This adapted communication is constructed as successful. As with previous examples, continuity is associated with effective communication (193-195) ‘especially someone whose seen her a few times’ perhaps constructing continuity as particularly important for people with learning disabilities.

5.4.3 The problem of assuming difference

Despite positionings of people with learning disabilities as lacking competence and of professionals as responsible to adapt to the needs of the individual, assuming difference in the abilities of people with learning disabilities was sometimes constructed as flawed. For example, treating the person as different to other patients by not providing the same information and opportunities that would be offered to people without learning disabilities was constructed as flawed.

In the examples below, Mark and Karen build accounts that assumptions of incompetence can limit the effectiveness of appointments.

Extract 11

759   **Mark:**  ... I’d prefer them (professionals) being more efficient um and to put a bit more detail with er the staff members or customers in general so they’ve got a fuller understanding. I know the capacity of some customers to take this on board would be different or if a staff member was to be able to get a accurate more describes or more detailed outcome of this is exactly what then that’d help us cause then we then learn how to further support customers within the diabetic community.

(Mark, line 759-766)

This example is taken from the interview with Patrick and follows Patrick stating that there is nothing he would improve about his appointments. As seen earlier, Mark constructs people with learning disabilities as having varying levels of ‘capacity’ to understand the
information given during an appointment (761-762), acknowledging this as a reason for professionals adapting the information they give. Drawing on a previously described repertoire that people need to be fully informed to enable them to manage their diabetes, Mark constructs incomplete provision of information as inadequate (759-761). Initially he positions both the person with learning disabilities and staff as needing to be fully informed. Later he emphasises the importance of informing staff who are implicitly positioned as more competent to understand (since their capacity is not in question) and they would be able to learn from a more detailed account and improve their support of the person’s diabetes management (763-766). Staff are constructed as playing an important ‘support’ role in the diabetes of ‘customers’ with learning disabilities and so need to be fully informed.

Extract 12

190 Interviewer: Do you think the doctors have a good understanding of learning disabilities?

191 Karen: No (laughter) not particularly um (.) I think I think more of the younger generation does but the old- the older doctors not so much. I think they’re still in the time where ‘well actually when I was training they were all lumped into one place and they weren’t really let out and they had and they it was really good for them there because they had a really good routine and they knew what they were doing everyday’ which is hhh a load of rubbish (laughter). So yeah they they say the odd thing sometimes you think oh hhh okaaay, that’s what you think like then.

194 Interviewer: Yeah, what sort of thing?

197 Karen: Well I think (.) they said - I think they said I think one of the most recent things was trying to get a referral in for healthy eating and he said ((changes to sceptical voice)) ‘well I think it’d be a bit of a waste of time’ sort of thing but but um we’ll just have to wait and see whether they answer it or not’ so those sorts of thing you think hhhhh.

(Karen, line 190-207)
The reported theorised views of older doctors viewing things as better in the past raises ideas of past treatment of people with learning disabilities involving institutionalisation, restrictions and control. Karen clearly distances herself from this view ‘a load of rubbish’. In these reported views Karen describes older doctors positioning people with learning disabilities as different; they need to be restricted in terms of place and choice and to have routine, having this in the past was ‘really good for them’ (193-196). This positioning of difference can be seen again in the reported speech of Pauline’s GP when trying to get a referral (202-206). Karen reports and acts out the doctor’s speech, strengthening and adding an evaluative element to her account (Wertsch, 2001). The doctor has assumed that Pauline lacks the ability to learn and improve her diabetes management, making putting effort into getting further help and advice ‘a bit of a waste of time’. This was said in a noticeably quieter voice to the surrounding talk, perhaps acknowledging that this is a controversial view and strengthening Karen’s positioning of herself as someone who finds this view unacceptable. Presenting contrasting categorisations in order to align with more liberal views around autonomy for people with learning disabilities has been previously observed in the accounts of support staff (Jingree & Finlay, 2008). In this reported speech, the doctor does not position themselves as responsible to make any effort on Pauline’s behalf, following up the referral is not a priority because getting her the support will probably not be worthwhile anyway (204-206). The doctor’s reported positioning of Pauline as different in her ability to benefit from a referral is therefore used to justify what Karen constructs as inadequate care.

5.4.4 People with learning disabilities are the same but different – managing the dilemma

Participants drew on potentially conflicting repertoires of difference and similarity to construct quality appointments: i) a quality appointment involves acknowledging that people with learning disabilities are different, ii) a quality appointment involves treating people with learning disabilities as the same as anyone with diabetes. These conflicting ideas produce an ideological dilemma (Billig et al., 1988) in that treating people with learning disabilities as the same as people without learning disabilities is constructed as both desirable and problematic in terms of providing quality care.
An example of this ideological dilemma and possible ways of managing it are illustrated in the extract below where Kamilla grapples with two dilemmatic positionings of people with learning disabilities: they are people the same as everyone else, they are different and professionals need a good understanding of the possible differences to provide good adapted care.

Extract 13

779  Kamilla: I think all the professionals as well should have a training um some
780  kind of training in understanding learning disability that they they
781  are still humans they’ve still got you know feelings they can still
782  understand even if it’s just partial um they should have some kind
783  of training on actually how to speak with those people with those
784  people, with people cause they’re not those people they’re just
785  people. They’re exactly the same they’re just ((changes to sing
786  song voice)) special in every kind of way but yeah I think all the
787  professionals should have some kind of training in in understanding
788  learning difficulties and how that can affect people...

(Kamilla, line 779-788)

Kamilla initially positions people with learning disabilities as like anyone else; they are ‘human’, ‘people’, have feelings and at least partial understanding. Some professionals are described positioning people with learning disabilities as lacking these qualities because they do not understand learning disabilities. Kamilla also positions people with learning disabilities as different from people without learning disabilities and each other, for example in the way professionals should speak to them and in their support needs. Professionals can only understand how to work with this population if they have specific training and experience (779 & 783-78).

Lines 783-786 clarify the ways in which people with learning disabilities differ. Having said that they are people like anyone else, Kamilla acknowledges her own use of the term ‘those people’ could be interpreted as categorising people with learning disabilities as different. People with learning disabilities are the same but ‘special’. The change in tone of voice to say this may acknowledge some difficulty with use of the term ‘special’. Similar to previous findings in staff talk about people with learning disabilities, Kamilla manages the dilemma
by flexibly categorising people with learning disabilities as either different due to disability or as ‘human’ and the same as everyone else (Jingree & Finlay, 2008).

Therefore, one way of managing the dilemmatic ideas of people with learning disabilities as the same and different was to differentiate the ways in which people are the same. They are the same on a broader more general ‘human’ level in their entitlement to the opportunity to be informed, involved and agentic in relation to their appointments and their diabetes care but different in their specific appointment related needs. Treating people as different in order to enable an effective positive experience contributes to the construction of a good quality appointment, treating people as different in their entitlement to information, involvement and choice constructs an appointment as flawed.

Summary of 5.4

Supporters constructed people with learning disabilities as ‘diabetes patients’ and so entitled to be the primary focus of appointments, with themselves in secondary supporting roles. However, the role of ‘diabetes patient’ for people with learning disabilities is constructed as uncertain and open to question. Professionals and staff may forget and position the person as irrelevant or having little role in their own appointment. This is demonstrated in the extracts above but also in the need to emphasise that people with learning disabilities are the patient, something that would generally be taken for granted in the context of a person with diabetes without learning disabilities during a primary care appointment.

People with learning disabilities were often constructed as different from other people with diabetes and so professionals and supporters were positioned as responsible for adapting appointments so that they would be effective for the individual. A quality appointment was constructed as one which acknowledged and accommodated the different needs of people with learning disabilities. Nevertheless, assumptions that people with learning disabilities are different and lack the competence to benefit from opportunities to improve their diabetes management were described to present care as of questionable quality. People with learning disabilities were constructed as different overall in their abilities to successfully complete some of the tasks involved in diabetes care appointments. However, they were also positioned as entitled to adjustments that enable effective appointments that meet their individual needs, and as ‘human’ entitled to the
same opportunities for learning and improvement as anyone else. Professionals and supporters have roles to fulfil to ensure this is achieved.

5.5 Repertoires of independence and choice

Participants drew on varying and sometimes conflicting repertoires around the need for independence and choice in relation to diabetes appointments. As seen in the interviews with participants with learning disabilities, different repertoires on independence positioned staff as having different levels of entitlement or responsibility to intervene so that support was constructed as necessary to varying degrees.

5.5.1 The importance of independence and choice

Participants drew on the repertoire that people with learning disabilities should have independence and choice in relation to their diabetes primary care appointments and diabetes care more broadly. This repertoire was drawn on frequently and by all supporters. Within this repertoire participants positioned the person they supported as having at least some level of independence and choice, with themselves and professionals as responsible to promote this. In evaluating the quality of diabetes care appointments, supporters often praised appointments structures and professionals that facilitated independence and choice and examples of barriers to these were cause for criticism.

Participants did not describe the people they supported as having a choice in whether to attend their appointments or whether to take part in assessments but in specific tasks such as preparing for appointments, checking-in, speaking to professionals and putting advice into practice afterwards.

Unlike the repertoire of difference discussed above, within talk on the importance of independence and choice, people with learning disabilities are positioned as like people without learning disabilities; they have a right to and ability to exercise independence and choice.

At times, participants described the person they support as having independence and choice in relation to their appointments. This involved positioning the individual as competent, appointment systems, staff and professionals as unproblematic and supporters
playing a limited role. In the example below, Sally positions Hayley as independent in relation to making her appointments so that staff have little involvement.

**Extract 14**

75  **Interviewer:**  No okay. So um Hayley was saying she makes the appointments herself are you ever involved in=

76  **Sally:**  =No not at all not at all. Like she says she gets a letter come through she er its it’s set out in a way that she understands it. I don’t think it’s easy read but it is out it tells her exactly what she needs to do and what what she needs to bring um and she will call and make the appointment and then she’ll call staff and say um if I’m not here she’ll let somebody know ‘I’ve got an appointment on on Wednesday or Thursday at this time’ so ((changes voice)) ‘okay just let us know how it goes’ and then she’ll just she’ll do that. But yeah she’s quite independent with all her appointments.

(Sally, line 75-85)

Sally positions Hayley as ‘quite independent’ with staff as having no or little involvement in the tasks of preparing for her appointments. The appointment system is supportive of this since the letter ‘tells her exactly what she needs to do’. Staff are positioned in a limited supporting role, she tells them when she is going to an appointment and lets them know how it went. Hayley is positioned as reliable to keep staff informed (81-83). Details of what Hayley does, including the reported speech of staff and Hayley herself build an account of appointment preparation as successful and unproblematic. At the end of this extract Hayley is positioned as experienced, knowledgeable and competent, making support unnecessary. This reflects Hayley’s own positioning of herself as independent and happy with her appointments.

Similarly, participants drew on the idea that the people they support should have choice in relation to their appointments. Below, Peter describes the people he supports as having control and choice over the level of support that they receive.
Extract 15

433  Interviewer: So um you go in you went into the appointments with both of them?
434
435  Peter: Um not every time David um has done the odd one on his own um and what I usually say is ‘just get the doctor to write down anything that you’ve got to do so that you can let us know so that we can help you with that’.
436
437  Peter: ... just sort of said to him ‘just just get the doctor to write down your levels so that we can just record it you know what they were’.
438
439  Peter: But yeah and they we always gave them the choice if they wanted us to come in and no certainly with Robert it’s a definite he would want you there but occasionally David would say ‘no I’m alright I’ll do it myself’ you know what he’s like
440
(Peter, line 433-448)

Peter describes David who has learning disabilities as having choice in whether he wants staff present during appointments. Peter reports his own speech to demonstrate this (434-436 & 443-444). Giving choice is constructed as consistent ‘we always give them the choice’ although the example given is one of necessity. This may perform identity work for Peter, defending against the potential view that going into appointments unsupported may be problematic. Peter uses minimising words to describe his level of involvement in each example of his reported speech, such as ‘just’. As with Sally, this is constructed as a straightforward process. Staff have a low level of input, they need a record of any changes and his levels. Peter ends by attributing David’s desire for choice to his personality ‘you know what he’s like’.

When supporters described themselves as providing support in relation to appointments, they emphasised the importance of supporting without taking over. This can be seen in the examples in section 5.4.1 where supporters emphasised the importance of supporting but not becoming the focus of communication with professionals. In relation to tasks around diabetes appointments, staff often described themselves as supporting, prompting and encouraging but positioned themselves as unentitled to take control. For example, Sally explains that staff ‘won’t ever make the appointment’ for Hayley but ‘we’d always yeah encourage and prompt her to do it.’ (Sally, lines 113-115).
5.5.2 Promoting independence and choice as problematic

In the example above, promoting independence and choice was constructed as unproblematic since the individual was positioned as competent and appointment related tasks were described as successful. However, participants sometimes constructed independence and choice in relation to diabetes appointments and diabetes management generally as problematic since given choice, the person they support may make unhealthy choices. This creates a dilemma for supporters who are positioned as responsible both for promoting independence and choice and ensuring the safety and wellbeing of the person they support. This repertoire was often drawn on to describe supporting people with learning disabilities to put advice from appointments into practice.

Peter constructs promoting independence and choice as necessary when supporting people after appointments but acknowledges that choice may not always lead to success in implementing lifestyle changes.

Extract 16

Peter: ... but it is about a lot of the time getting people to see the bigger picture and the the longer term um and probably a lot of a lot of the things that changed after an appointment were down to the fact that you know we’d we’d listened and and maybe read stuff that we’d been given and sort of together but again you can’t make people do stuff however hard you try um if you think it’s right whether you think it’s right they’ve got to want to do it every time

Interviewer: Mmm yeah

Peter: so it’s about educating people and and you know getting across the benefits to them so

(Peter, line 978-987)

Appealing to wider discourses including the principles that underpin the Mental Capacity Act, Peter positions staff as unentitled to make people they support do something they don’t want ‘whether you think it is right’ (983-984). Such statements function to build Peter’s identity as a believer in choice and independence for people with learning disabilities. Staff are positioned as responsible to support people by encouraging them to choose to make changes by going through information with them, trying hard and
educating people. Working with the people they support to help them choose to put advice into practice is presented as successful since change has followed this process (980). This also positions people with learning disabilities as lacking the ability to 'see the bigger picture' and the benefits of putting advice into practice without the support of staff. Staff are positioned as more competent to understand the benefits and explain these to the people they support. This shows similarities to previous findings that support staff increase autonomy through discussions that allow people with learning disabilities to reformulate their goals and wishes (Hooren, Widdershoven, Borne, & Curfs, 2002) and describe themselves as encouraging safe/healthy diabetes care without taking control (Rouse & Finlay, 2016; Whitehead et al., 2016). Although staff are not entitled to force people to do something they don’t want (982-983), they are responsible for trying to help them to choose the option that is best for them. This shows similarities with previous findings that staff who support people with learning disabilities construct independence and choice as guided and promoted within safe boundaries (Jingree & Finlay, 2008; Rouse & Finlay, 2016). Although such talk draws on discourses of rights relating to the legal framework of the Mental Capacity Act (2005), no supporter explicitly referenced the Act or any formal assessment of capacity.

In the extract below, Karen constructs independence and choice as problematic by positioning the person she supports as unreliable and likely to engage in risky diabetes management.

**Extract 17**

7  Karen: ...she’ll go up in her room and she’ll binge on crisps and chocolate and sweets
8
9  Interviewer: Right yes
10  Karen: but she’s also eating it laying down so it all just sort of sits and at one point they actually thought she was an alcoholic, her her liver was so bad that they thought that she was sneaking alcohol and we said ‘no it’s [literally all down to eating] and how she lays’ and
12  Interviewer: [It’s the food] okay yes yeah
Karen builds a strong case that Pauline’s behaviour is unhealthy and dangerous; her eating has damaged her liver to the extent that the doctors thought she was an alcoholic. Pauline is positioned as unreliable to independently put healthy eating advice into practice. Karen goes on to defend against the potential accusation that staff should prevent this risky behaviour by positioning Pauline as competent to understand and as therefore having capacity (15-19) ‘she knew it’s bad for her but she still did it anyway’. Staff awareness that Pauline ‘knew’ her eating behaviour was bad for her indicates a formal or informal assessment of capacity which was not explicitly described. The reported theoretical speech of staff intervening (16) is presented as authoritarian, strengthening Karen’s account that this approach would be wrong. It is Pauline’s understanding that entitles her to independence and choice and limits staff entitlement to intervene. Again, not intervening with the unhealthy choices of someone who has understanding is in line with the principles of the Mental Capacity Act that everyone has the right to make an unwise decision.

As found in previous research with support staff, capacity can become problematic; it means Pauline must be allowed to make an unwise choice. Strikingly, and in common with previous findings (Rouse & Finlay, 2016), elsewhere, staff were constructed as entitled to intervene with the right to choice when it came to activities in the presence/control of staff such as staff prepared meals. In fact, Karen described hiding fruit and vegetables in Pauline’s meals without her knowledge and against her choice. ‘I’ll cut fruit and veg up quite small and so if it’s in her food she barely notices it and she’s eating it without even realising’ (Karen, line 393-395). This draws on the idea that supporters know what is best for Pauline and in this case are entitled to override her choice.
5.5.3 Repertoires of dependence and control

In conflict with the idea that people with learning disabilities should have independence which supporters are responsible to promote, participants also sometimes positioned people with learning disabilities as dependent on support for the appointment process to be effective and themselves as taking control of specific appointment related tasks.

As seen in section 5.3, people with learning disabilities were sometimes positioned as lacking in cognitive, social or emotional competence and therefore dependent on support. For example, Kamilla constructs support from someone he knows as essential for Patrick, including taking over answering questions during appointments.

Extract 18

Kamilla: Um obviously sometimes if the doctor gonna ask the question Patrick can um sometimes get a bit confused even if he knows the answer er but he will be like ‘oh me don’t know me don’t know’ so then obviously staff gonna step in and and just explain it’s like ‘that’s what’s been going on’. Um if it’s something which Patrick knows he shouldn’t be doing like I mentioned the wrappers after chocolate he gonna get really upset, start crying and everything but um he knows that staff needs to say that so so he he knows when he shouldn’t be doing things and he doesn’t like when obviously it’s pointed out to him ...

Um so yeah so if he’s not sure about the answer the staff gonna obviously give the answer to the professional er because like I said it’s always the staff who who know Patrick very well so it’s not like someone completely new who doesn’t know him and then they ask question about his health it’s like mmm I don’t know, it’s like no there’s always someone who knows Patrick.

(Kamilla, 216-231)

Kamilla constructs Patrick, who has type 2 diabetes, as different to other people with diabetes; he may not tell professionals the truth about his eating behaviours and could become confused and upset (216-224). Patrick is positioned as lacking cognitive competence (he may become confused or unsure) and emotional competence (he may
start to cry). Kamilla also positions Patrick as unreliable in his eating behaviours and his ability to accurately and honestly inform professionals about his diet (217-221). Staff are implicitly positioned as more competent to communicate accurate information to the professional about Patrick’s diabetes management to professionals than Patrick (226-228). Patrick ‘knows when he shouldn’t be doing things’ placing responsibility for his risky eating behaviours with Patrick and away from staff. Kamilla builds an account that having someone who knows Patrick well to ‘step in’ and answer questions is essential. Drawing on an ‘individual pathology’ discourse (Wilcox et al., 2006), Patrick’s dependence on others to support communication with professionals is attributed to internal and unchangeable reasons and is overcome through support rather than changes to the appointment or Patrick himself. Since the professionals do not know Patrick and need information, the only option is for supporters to step in and give the information he would prefer not to share.

Mark describes himself as taking control of tasks such as making appointments and ensuring their regularity in line with organisational practices.

Extract 19

106 Mark: Well between your keyworker and your other members of staff we make the appointments as according they as to when when we need them um through support plans that we provide as part of our care plan um we then make the appointments dependent on when they are needed so the health reviews essentially his diabetes reviews every six months to a year’s time and that’s what’ll go through then to make sure they’re in date and every review is conducted appropriately and on time as well.

114 Interviewer: Right yes.

115 Mark: Um because if we miss a review ( ) is then out of date our care plan is then falling behind on what we’re trying to provide each time.

(Mark, line 106-116)

Staff are positioned as responsible to ensure appointments are made and that they are timely, in line with care plans (106-113). Missing diabetes reviews is constructed as inadequate support. Unlike the previous examples, here Mark does not attend to the idea
that Patrick should have any choice in whether to make or attend regular appointments. This contrasts with Sally’s description of Hayley as independent in making her appointments and staff as unentitled to intervene, perhaps because Hayley is positioned as reliable and unlikely to miss appointments.

5.5.4 Independence and choice vs dependence and control - supported independence and guided choice

As described in the two sections above, supporters drew on conflicting repertoires of independence and choice as important, safe and successful (the person is competent and health services facilitate independence and choice) and risky and unsuccessful (the person can choose not to put advice into practice and neither professionals nor staff can force them). Supporters are therefore positioned in different roles, as responsible to promote independence and choice in relation to diabetes appointments and as responsible to ensure successful appointments and safe effective management. This is an example of an ideological dilemma (Billig et al., 1988). One way of managing this dilemma was to make use of positionings of competence and incompetence and to define independence and choice as bounded. An example of this can be seen in the extract from Karen.

Extract 20

Karen: ... Um well it’s making sure that (. ) appointments are booked and if you see a letter that’s followed up straight away. Um if she has any questions or maybe when we’re out and we’re seeing her picking up a big bag marshmallows perhaps saying ‘well actually Pauline they’re probably not the best for you’. Whether she then chooses to buy them anyway at least you know that you’ve given that advice and it’s recorded when you get back but it’s it’s just making sure she is guided and supported along the way and just offering those bits of advice and remind- gentle reminders because at at the end of the day yes she is an adult but does she really understand the consequences of what she’s putting in her body, probably not.

Interviewer: Yes yeah right.
Karen: Someone’s told her but she’s probably thinking (.) ‘it’s not happened for the last twenty odd years or however long so I’m alright…

(Karen, line 691-706)

In this extract Karen positions staff as entitled to intervene in two areas relating to diabetes care appointments; they can check timely appointments have been made (691-692), they can guide Pauline to put healthy eating advice into practice (693-701). Karen does not justify the need to check appointments are made but implies a questioning of Pauline’s competence in this area. This may draw on the idea that staff have an overall responsibility for the welfare of the person they support and presents timely appointments as important. This idea can be seen in the description of staff recording when they have prompted healthier choices (695-696).

To explain staff intervention ‘guiding and supporting’ Pauline about her diet, Karen positions Pauline as lacking in a specific type of cognitive competence. Pauline is constructed as having only partial understanding, the kind of understanding she lacks in relation to long-term consequences, knowledge that might prevent over-indulgence in sweet treats. This is in contrast to Karen’s previous positioning of Pauline as having capacity (in extract 16) and could open her to the accusation that staff are unentitled to intervene. Karen acknowledges and questions the potential alternative positioning of Pauline as an adult with the right to choice around her diet: ‘yes she is an adult but…’.

Karen then clarifies Pauline’s understanding to a level which entitles staff to guide her choices. In Karen’s earlier positioning of Pauline as having capacity, staff were ‘not allowed’ to tell her what to do. Here, since Pauline lacks this specific understanding of the consequences of her behaviour, staff are positioned as having a responsibility to ‘offer’ advice and ‘gentle reminders’. Implicit references are made to the principles of the Mental Capacity Act (2005), staff reported speech illustrates (694-695) a suggestion rather than forbidding her from buying sweets; Pauline is advised, guided, supported and ‘gently’ reminded. The choice whether to buy the sweets remains with Pauline but staff have fulfilled their responsibility to guide her choice.
Summary of 5.5

Supporters regularly positioned themselves as responsible for promoting independence and choice in relation to diabetes appointments and as unentitled to take control of appointment-related tasks. In contrast, supporters sometimes described themselves taking responsibility for tasks and taking over. In this context, people with learning disabilities were sometimes constructed as lacking in competence and dependent on support and guidance to make appointments successful and to ensure good and safe choices. This led to constructions of independence and choice as problematic since supporters have potentially conflicting responsibilities to promote independence and choice and ensure effective and safe appointments and diabetes care. One way in which supporters managed the conflicting repertoires around independence and choice in diabetes appointments was by appealing to ideas of competence, capacity and understanding. Supporters drew inconsistently and implicitly on the principles of the Mental Capacity Act (2005) to construct themselves as restricted in their ability to intervene in unhealthy choices although they did sometimes construct themselves as responsible to encourage and prompt healthy behaviours.

5.6 Chapter summary

This chapter has described four key interpretative repertoires that supporters drew on in relation to quality diabetes primary care for adults with learning disabilities: the purpose of appointments, the knowledge of stakeholders, the roles and responsibilities of stakeholders and repertoires of independence and choice. Quality care was constructed as: providing a positive and motivating experience, stakeholders fulfilling their roles and responsibilities, and promoting/respecting independence of people with learning disabilities. Effective care was also informed by supporters’ experiential knowledge of the person, their needs and preferences. Ineffective care failed to motivate or frightened the individual, made unsuccessful diabetes care decisions based on medical rather than experiential knowledge of the individual and failed to support independence and choice.

Within these repertoires, supporters made use of varying positions of themselves, people they supported and healthcare professionals. People with learning disabilities were sometimes positioned as different from other people with diabetes in their need for a ‘relaxed’ non-censuring approach, adapted appointments and dependence on others to
support successful accessible diabetes care. On the other hand, people with learning disabilities were also positioned as the same as other people with diabetes in their rights to take a proactive role in their appointments and be the focus of communication, in their right to choice in their diabetes management and their entitlement to be treated with the same respect as other people with diabetes. Accounts of good care positioned healthcare professionals as having good knowledge of the person with learning disabilities or taking on board advice from supporters whose knowledge was often constructed as more valuable in ensuring appointments were successful in motivating good diabetes management/lifestyle changes. At other times supporters positioned healthcare professionals as medically knowledgeable but lacking experience of the person. This allowed supporters to construct their own professional knowledge of the individual in contrast.

Similarities and differences in the construction of quality care by supporters compared to people with learning disabilities were also highlighted. Both positioned professionals/appointments which were not adapted to the needs of the individual e.g. in terms of communication, as flawed/inadequate. Supporters’ constructions of people with learning disabilities as entitled to independence and choice shows similarities to the way some people with learning disabilities drew on accounts of restrictions to independence and choice to build accounts of flawed/inadequate care. A distinction is that supporters sometimes constructed this as a right with implicit reference to the principles of the Mental Capacity Act, whereas people with learning disabilities made reference to moral rather than legal rights. Furthermore, unlike people with learning disabilities, supporters constructed the need to uphold independence as problematic which may reflect the need to account for positionings and socially available ideas of supporters as having overall accountability.

The discursive resources described here and the ways they were employed by supporters functioned to manage identity. Conflicting repertoires were managed in ways that built positive identities for supporters attending both to their dual responsibilities to promote the individual’s independence and rights to choice and their accountability for the health and wellbeing of the people they support. This was done by making use of positionings of (in)competence, ‘bounded empowerment’ and implicit references to the principles of the Mental Capacity Act. The ways in which supporters construct quality care has implications for the diabetes care of people with learning disabilities including the level of independence and choice people with learning disabilities have in terms of their diabetes care appointments.
Chapter 6   Findings iii) Healthcare professionals’ constructions of quality diabetes primary care appointments for adults with learning disabilities

This chapter focuses on the analysis of five interviews with healthcare professionals about their experiences of clinical encounters with adults with diabetes and learning disabilities within primary care. Participants were: three Nurse Practitioners and one GP, all of whom had a specialist interest in diabetes, and one Advanced Diabetes Dietician. All had experience of consultations with at least one person they identified as having mild-to-moderate learning disabilities within GP surgeries. Three participants, Alison (Advanced Diabetes Dietician), Amanda (Nurse Practitioner) and Hilary (Advanced Nurse Practitioner), also had experience of conducting consultations and education sessions within supported living environments (see table 3 in the methods chapter for full details). Healthcare professionals were recruited separately from people with learning disabilities. However, during the interviews three professionals appear to discuss involvement with two of the participants with learning disabilities (see methods section for further details).

6.1   Overview

This chapter explores the key interpretative repertoires and subject positions used by healthcare professionals in their constructions of quality diabetes care for people with learning disabilities. Conflicting repertoires around people with learning disabilities as the same and different to other people with diabetes and the ways in which these were used to flexibly construct quality diabetes care appointments are also considered.

The four sections below explore the following four key interpretative repertoires drawn on by healthcare professionals: i) Primary care diabetes appointments have goals that should be achieved, ii) all stakeholders should fulfil their roles and responsibilities, iii) the quality of care that healthcare professionals can provide is constrained by difficulties that are outside of their control and iv) successful decisions about diabetes care are made by those with medical knowledge of diabetes alongside experiential knowledge of the individual.
6.2 Constructing the purpose of diabetes primary care appointments

Healthcare professionals drew on the overall idea that diabetes appointments for everyone aim to improve diabetes care and outcomes by achieving two key purposes: i) to complete care processes according to standard guidelines, ii) to educate and advise people with diabetes (and supporters) about their condition in order to inform good day-to-day diabetes care. When considering diabetes appointments for people with learning disabilities specifically, appointments were sometimes constructed as having the further (and sometimes conflicting) aim of ensuring that the person with learning disabilities has an untroubling or positive experience. This aim sometimes conflicts with the first two purposes described above, since people with learning disabilities were often positioned as different in their cognitive abilities and emotional competence, making participation in care processes and consultations about their diabetes a difficult and potentially distressing experience. The talk of professionals on the goals of consultations shows similarities to the repertoires drawn on by people with learning disabilities and their supporters on the purpose of appointments. Professionals differed from other participants in that failure to fully achieve all appointment aims was not constructed as constituting inadequate care.

6.2.1 Diabetes appointments should achieve the same goals for everyone

All healthcare professionals drew on the interpretative repertoire that diabetes appointments in primary care have the same purpose regardless of whether the person has learning disabilities. Within this repertoire professionals described people with learning disabilities as entitled to the same care processes and advice to inform their day to day diabetes management as anybody else with diabetes. Due to limited space the examples in this section focus on discussion of the aim to achieve recommended care processes.

Amanda, a Nurse Practitioner, explains that people with learning disabilities should receive the same checks as everyone with diabetes.
Extract 1

584  Amanda:  ...they’re entitled to all the same checks as everyone else
585  so just to understand you know why are we doing your
586  blood pressure and looking at your feet and weighing you
587  and doing your blood tests and
588  Interviewer:  Yes yeah
589  Amanda:  yeah so I’d say the same as everyone else but with a bit
590  more time um and understand their needs

...  

650  Amanda:  Yeah I mean there was a um about fourteen levels points
651  that everyone should be having of the you know the as I
652  said the bloods, the eyes, the feet the der der der,
653  fourteen points of care that everyone should expect if
654  they have diabetes.
655  Interviewer:  Yeah that’s the NICE=
656  Amanda:  =The NICE guidelines yeah.

(Amanda, line 584-656)

Amanda constructs receiving ‘checks’ or ‘points of care’ as an important part of diabetes appointments for ‘everyone’, bringing in the authority of the NICE guidelines to strengthen her point (650-656). This aim of diabetes appointments is constructed as the same regardless of whether or not a person has learning disabilities (584-585, 589-590 & 653-654). They are ‘entitled to the same checks as everyone else’ and the ‘points of care’ are what ‘everyone should expect if they have diabetes’. People with learning disabilities are positioned as potentially different in that they may need more time and have ‘needs’ that the professional should understand (589-590). Difference is played down using minimising words ‘the same as everyone else but’, ‘just to understand’ and does not exempt them from the same tests as everyone else (584, 589-590). In evidencing her knowledge of the points of care and describing herself as covering these for all patients, Amanda positions herself as knowledgeable and conscientious. As discussed in previous chapters, categorisation is a powerful way of ordering the world (Potter & Wetherell, 1987). In referencing NICE
guidelines, a document that sets out the care expected for everyone with diabetes (and
does not distinguish between people with and without learning disabilities), Amanda is
categorising people with learning disabilities according to their membership of the category
‘people with diabetes’. Here, the rights/expectations of this category are not negated by
their membership of the category ‘people with learning disabilities’.

Dr Jones, a GP, similarly constructs completion of care processes as an important goal of
diabetes appointments for people with learning disabilities.

Extract 2

1286  Dr Jones:  ...So um so I think when you’ve got someone with
1287  learning disability there is a danger that you um focus on
1288  the illness experience um and you don’t do the elements
1289  of care that have been shown to be associated with
1290  outcomes and you say well you know they’ve suddenly
1291  become less important because the person has got
1292  learning disability. So I think I would counsel against that
1293  cause I think then like I said early on if someone’s got a
1294  learning disability then has a stroke their ability to
1295  manage a stroke is much less than someone without
1296  learning disability so I do think it’s important that we still
1297  have a focus on the disease aspects and so then when
1298  you say what’s a quality consultation well I think a quality
1299  consultation for someone with learning disability is one
1300  that fully integrates both those aspects...

(Dr Jones, 1286-1300)

As in extract 1, Dr Jones constructs ‘elements of care’ as a necessary part of appointments
for everyone with diabetes and references scientific research to lend weight to his
argument ‘elements of care that have been associated with outcomes’ (1288-1289, 1296-1297). People with learning disabilities are positioned as different to other people with
diabetes in that they have a reduced ability to manage poor outcomes such as stroke
(1293-1296). This constructs achievement of care processes (which are ‘associated with
outcomes’) as more important for this population (1295-1297). People with learning
disabilities are further positioned as different in that having learning disabilities may lead
professionals to approach their consultations differently (1286-1292). Citing the example of the potentially serious outcome of a difficult-to-manage stroke, theoretical appointments which shift the focus from the ‘disease aspects’ to the ‘illness experience’ for someone with learning disabilities are constructed as inadequate and potentially dangerous. Instead, a quality appointment should ‘fully integrate both those aspects’ (1298-1300).

6.2.2 Diabetes appointments for people with learning disabilities prioritise experience

Despite constructing appointments for people with learning disabilities as having the same goals of achieving care processes, four professionals also drew on the repertoire that diabetes appointments for people with learning disabilities should focus on ensuring a positive experience.

In contrast to Dr Jones in the extract above, Linda, an Advanced Nurse Practitioner, explains why appointments with people with learning disabilities should focus less on health issues and more on the person.

Extract 3

30 Linda: ...and actually we find that we just have to be more smart with our timing cause they don’t want to sit in here for too long
31
32
33 Interviewer: Yes yeah
34 Linda: um because a lot of them just you know they’re here they - you’ve got to be quite chatty and appreciating them as a person, they’re less interested in the healthcare side of it so we’re trying to do a bit of everything as we go along in a fairly chatty style and then fill out the necessary bits later.
35
36
37
38
39
(Linda, 30-39)
Linda constructs a good appointment as less ‘health structured’ and more focused on ‘appreciating them as a person’. Since people with learning disabilities are positioned as different in their willingness to spend time on the consultation and in their level of interest in healthcare issues, prioritising focusing on the person rather than health issues is constructed as more productive (30-37). Describing the need to shift focus from healthcare issues to their ‘story’ and their interests also implicitly positions people with learning disabilities as less competent to manage more serious aspects of diabetes (883-886). Although Linda refers to tasks she needs to complete (37-39), interaction with the person is ‘chatty’ and focuses on lighter topics ‘so we’re trying to do a bit of everything as we go along in a fairly chatty style’. This may reflect the tendency of people with learning disabilities to construct appointments as discussing positive rather than problematic topics and supporters’ constructions of good appointments as positive and motivating.

In line with the idea that people with learning disabilities are different and their appointments should be less health focused, three participants described prioritising avoiding discomfort or distress over achievement of care processes.

Linda explains that blood tests for people with learning disabilities and diabetes are not ‘forced’.

Extract 4

489 Linda: Most of them are actually very - they’re okay and we have very good phlebotomists and we get to know them.
490 ... we’d never forced them and you know if it if it isn’t essential we’re not going to we’re not going to make a fuss.
493

(Linda, line 489-493)
Linda: um but they might be having an off day or if they haven’t been drinking very much and they’re actually very dehydrated we’ll send them away and say go and drink more because we won’t be able to get the blood test, it’ll be too difficult, then it’ll be painful and then they won’t like it so we won’t do it.

(Linda, line 517-522)

Within this extract Linda can be seen attending to the idea that achieving assessments is important by describing efforts to ensure success; the phlebotomists are ‘very good’, the situation where the test may not happen is ‘if it is not essential’, people may come back when success is more likely (489-490, 517-520) and most of them are ‘okay’. This constructs a scenario where people with learning disabilities do not receive blood tests as unlikely. However, people with learning disabilities should not be ‘forced’ and the professionals won’t ‘make a fuss’. Linda describes the scenario in which the blood test is not done as one which the person will dislike because it is ‘painful’. Here, good care makes the effort to enable assessment but sometimes prioritises avoiding discomfort over successful completion of care processes.

Hilary, a Nurse Practitioner, explains why achieving care processes is not the main component of a ‘good’ diabetes appointment for people with learning disabilities.

Extract 5

Interviewer: What’s a good diabetes appointment for a patient with learning disabilities?

Hilary: Well number one not to distress them and to achieve what is achievable and you know like I said you know there was no way he could have eye screening and there was lots of times I couldn’t examine his feet and I had to accept that you know um perhaps if I’d taken him home with me and (laughter) you know after about twelve hours he might let me look at his feet. It’s impractical and you know I think we need to be realistic with people with learning difficulties.

(Hilary, line 425-434)
Hilary constructs diabetes appointments for people with learning disabilities as having different goals. The primary aims are to avoid distress and ‘achieve what is achievable’. Hilary describes the limitations experienced when working with one individual (429-433) but generalises this difference to all people with learning disabilities (427-428 & 433-434) ‘we need to be realistic with people with learning disabilities’. Hilary invokes practicalities talk to explain why some assessments cannot always be achieved, including giving an unviable scenario as the only way to complete foot checks (she cannot take him home with her). This shows similarities to the practicalities discourses and the practice/principle rhetorical device previously identified in discourse analytic work (Wetherell, Stiven, & Potter, 1987) including in talk about people with learning disabilities by care staff (Jingree & Finlay, 2008, 2013). It is also comparable to people with learning disabilities constructing their disability as a difficulty or barrier to diabetes care in chapter four. The work Hilary does to justify unsuccessful care processes demonstrates the prevalence of the repertoire that assessments are important. By building a strong case against the viability of completing care processes, Hilary defends her identity as a competent healthcare professional.

6.2.3 Managing the dilemma – repertoires of practical and person-centred care

Within the interviews with healthcare professionals, conflicting ideas can be seen on what constitutes a good quality diabetes care appointment for people with learning disabilities. Healthcare professionals drew on the idea that good quality care for this population should meet the recognised standards and quality guidelines for diabetes care. Healthcare professionals also drew on the repertoire that good diabetes care should adapt to the needs of this population which may necessitate deviating from quality standards. This is an example of an ideological dilemma (Billig et al., 1988). The idea that good diabetes care should involve completion of care processes such as blood tests, foot checks and eye screenings was frequently drawn on and is found in diabetes care information, standards and guidelines (Diabetes UK, 2016a; National Institute of Health and Care Excellence (NICE), 2015). As seen in section 6.2.2 of this chapter, despite positioning people with learning disabilities as entitled to the same care as anyone with diabetes, participants also described occasions when people with learning disabilities did not successfully receive all recommended care processes. To manage this dilemma and defend a competent professional identity, participants redefined the standards by which quality diabetes care is assessed when considering this population.
In the example below Hilary explains why differences in what can be achieved in diabetes care for a person with learning disabilities should not be viewed as difference in quality.

**Extract 6**

459 Interviewer: Do you think there’s a difference in the quality of appointments if a patient has got a learning disability?

460 Hilary: It’s not – quality is the wrong word really

461 Interviewer: Right yes

462 Hilary: there are differences but then it’s not to do with quality um like I said it’s a lot to do with expectation you know (.) you - I could not do everything I wanted to do without um without causing distress and confusion and I had to tailor everything

467 Interviewer: Yes yes

468 Hilary: you know I mean I spent a lot of time with him, more than any other fifty year old insulin type two you know I had to spend a lot of time with him and he had a lot of time with other carers and other people and hospital admissions. He had ketoacidosis when he had um a chest infection once you know so he had to go in for that which might not have happened if somebody was saying you know ‘I’m getting short of breath and I don’t feel too good’ you know.

476 Interviewer: Yeah mmm

477 Hilary: He’s physically at a disadvantage which currently you know there is no mechanism for for bridging that gap you know and I wouldn’t like to say it was a lack of quality (laughs).

(Hilary, line 459-479)
Hilary challenges the idea that any differences in what was achieved during appointments for this individual can be viewed as difference in quality. The extract starts and ends by arguing that difference is not equated with quality (463-465, 477-479). The person with learning disabilities is positioned as different; he lacks emotional competence, needs more time and is ‘physically at a disadvantage’ when it comes to communication (465-66, 473-468-471, 473-477). Trying to do ‘everything I wanted’ was therefore constructed as inappropriate because it would cause ‘distress and confusion’ (465-466). This means that she ‘had to tailor everything’, drawing on discourses of good care as person-centred.

Furthermore, differences in people with learning disabilities were described as limiting the quality of health outcomes that can be expected – the person was physically unable to communicate and there is ‘currently’ ‘no mechanism for bridging that gap’ (477-479). This makes use of practicalities rhetoric (Wetherell et al., 1987); it is impractical to expect the same health outcomes for someone who cannot communicate how they feel.

Hilary positions herself as competent and conscientious. A case is built that more than usual effort was put into this person’s care; care was ‘tailored’ (466), extra time was spent with him and he received attention from other professionals (468-470). This defends against the possible interpretation that not achieving ‘everything I wanted’ was due to lack of effort or inadequacies in healthcare. Hilary therefore defines diabetes care for this individual as different but not of lesser quality. Since he/people with learning disabilities are different, care is tailored and ‘expectations’ of care are redefined. Quality care is person-centred and realistic.

Similarly, when considering people with learning disabilities as a population, Amanda constructs adequate diabetes care as individualised and doing your best.

Extract 7

Amanda: Um some people might not like you to look at their feet or might find it frightening having blood test taken

Interviewer: Right yes yeah.

Amanda: that sort of thing but if you sort of explain it in a calm way then um hopefully they’ll go on board with that.

Interviewer: Yes yeah
People with learning disabilities are positioned as different from those without learning disabilities in that they might dislike and fear checks (284-285). Amanda attends to the idea that achieving assessments is important. She describes the efforts made to persuade people and constructs this as likely to be successful ‘hopefully they’ll go on board with that’ (287-288). People with learning disabilities are also positioned as different from each other (290-292). What can be achieved depends on the severity of learning disabilities and the responsibility of the professional is to ‘try’ and ‘do the best’. Like Hilary, Amanda constructs good care as person-centred: ‘you just have to judge according to that individual’ (290-295).

Participants therefore made use of positionings of people with learning disabilities as different to redefine the standards according to which quality diabetes care for this population is judged. This allowed healthcare professionals to manage the dilemmatic ideas that i) quality care should achieve the same goals for people with and without learning disabilities and ii) that the goals of quality care should be different/adapted for this population. Since people with learning disabilities are different their care should be person-centred or ‘tailored’ to the individual. Since people with learning disabilities lack emotional competence, professionals should prioritise minimising distress over achievement of care processes. Differences also place constraints on outcomes, so that quality is constructed as making an effort and doing your best but being realistic and sometimes adjusting expectations. Use of these discursive strategies allowed professionals to construct care as good or equal quality and to defend a positive professional identity whilst describing care that does not meet the recommended guidance.
Summary

Professionals drew on the repertoire that like anyone with diabetes, people with learning disabilities should receive the care processes set out in the NICE guidelines. This repertoire constructed a good diabetes appointment as one which does not exclude people from these processes because they have learning disabilities. People with learning disabilities were positioned as the same as others with diabetes. On the other hand, quality care for people with learning disabilities was constructed as prioritising experience over achievement of care processes. Within this repertoire people with learning disabilities were positioned as different from other people with diabetes. These conflicting repertoires present an ideological dilemma (Billig et al., 1988), which speakers managed by constructing quality care as practical and person-centred. Achieving some appointment goals such as blood tests and some screenings recommended by the NICE guidelines was constructed as distressing and/or impractical. For this population a good appointment may accept the limitations of working with people with learning disabilities by taking a less health focused approach that does not insist on care processes that might cause distress.

6.3 Roles and responsibilities

As seen in the previous data chapters, participants here assessed quality according to whether stakeholders fulfilled their roles and responsibilities. For professionals, the roles and responsibilities that stakeholders had were dependent on whether people with learning disabilities were constructed as the same or different from people without learning disabilities. People with learning disabilities were positioned as the same as others in that they should play an active role in their appointments. People with learning disabilities were positioned as different in that adaptations may be needed to make appointments and care effective. For an appointment to be ‘good’ people with learning disabilities should play an active role in their diabetes care and supporters and professionals have a responsibility to ensure that they are able to do so despite possible differences due to their disability.
6.3.1 People with learning disabilities as actively engaged patients

Like people with learning disabilities and their supporters, professionals often constructed people with learning disabilities as proactive patients; they should be the focus of the consultation and play an active role in their appointment and diabetes care more broadly. Since people with learning disabilities were constructed as inconsistent in their competence to understand, engage and self-manage, their involvement was sometimes constructed as limited and supported. People with learning disabilities were therefore constructed as having a role to proactively engage in their appointments and professionals and supporters as responsible to encourage and support their involvement.

Dr Jones discusses the importance of involving people with learning disabilities in their diabetes care.

Extract 8

1071     **Dr Jones:** I think to take away the responsibility from the individual patient is is potentially not a good thing.
1072
1073     **Interviewer:** Right yeah
1074     **Dr Jones:** I mean their responsibility for their own health and then accessing healthcare it’s important that they are aware of that and that they have a role in that. Um er I don’t think that - managing a condition like diabetes is not a passive thing. Er it’s about the decisions that one makes every day and I think accessing healthcare is part of that. I think the issue is where if we’re saying it’s the person’s responsibility but then they’re unable to fulfil that responsibility then we have to have safety nets that make sure that we can then have a - have something a different approach that means they don’t fall through the net and then when that happens the outcomes get a lot worse

(Dr Jones, line 1071-1085)
Since diabetes is a condition that requires active management, people with learning disabilities are constructed as patients with some responsibility for their health (1071-1079). Dr Jones constructs the person and professionals as having different types of responsibility. The person has some responsibility for actively managing their health including accessing healthcare (1074-1076). In this sense people with learning disabilities are implicitly positioned as being like other diabetes patients. People with learning disabilities are then positioned as potentially different (1080-1084) in that they may lack the competence to fulfil their responsibility. In this case ‘a different approach’ is needed. Overall responsibility is placed with more competent others - ‘we’ - to provide a safety net to avoid poor outcomes if the individual is unable to fulfil this responsibility themselves (1084-1085). Placing responsibility solely with people who may lack ability to manage their diabetes is constructed as poor care (1084-1085) because ‘when that happens the outcomes get a lot worse’. This shows similarities to previously identified positions of people with learning disabilities having a level of responsibility but that overall responsibility lies with more competent others (Rouse & Finlay, 2016). People with learning disabilities therefore should have some involvement and responsibility but with back-up from others if needed. 

Similar to supporters in the previous chapter, professionals constructed the individual with learning disabilities as the patient and so the focus of the consultation.

**Extract 9**

414  **Linda:**  I will always sit my patient whoever it is in that chair
415  
416  ((indicates chair nearest to her)) and I will always put the carer in that chair ((indicates chair furthest from her))
417  **Interviewer:**  Right
418  **Linda:**  and I will always try and say you know welcome them you know and try and pitch it at their level. Now sometimes they they don’t want to interact because the parent’s always done it for them or the carer does it for them.
422  **Interviewer:**  Yes yeah
Linda constructs the person with learning disabilities as the patient and so the focus of the appointment. This is done physically through seating arrangements, in the way she directs her initial interactions and by describing asking for permission before involving carers. Linda also positions people with learning disabilities as different; she needs to ‘pitch it at their level’, interaction may only focus on the individual initially and her attempts to communicate with the individual may be unsuccessful. This raises the possibility that focusing on the person is important as a ‘respectful’ courtesy but is not necessarily productive. As in section 6.2 Linda draws on the repertoire that appointments for people with learning disabilities may aim for but not always achieve the same goals.

6.3.2 The role of supporters

All professionals constructed supporters as having a valuable role in conveying knowledge of the home experience during appointments and reinforcing information from appointments at home. In these cases, support was constructed as enhancing the quality of diabetes appointments. Participants also drew on the idea that quality of care can be compromised when supporters fail to fulfil their responsibilities to support people with learning disabilities to engage in their diabetes care. Ways in which supporters were constructed as not fulfilling their responsibilities included being critical of the individual, not sharing information, and not keeping track of appointments.

Alison, an Advanced Diabetes Dietician, explains what is different about the quality of appointments for people with learning disabilities.
Alison describes the likelihood of non-attendance (DNAing) as a way in which the quality of appointments may differ for people with learning disabilities. Initially Alison considers the possibility that quality may be different for this population ‘I don’t know I mean may- hhh possibly’ a device described as ‘stake inoculation’ (Abell & Stokoe, 1999). This allows Alison to present herself as unbiased and able to think critically about healthcare practice. Alison then acknowledges possible reasons for non-attendance that may be within the control of professionals and healthcare systems (previous appointments may have felt uncomfortable or not worthwhile or they may become ‘lost in the system’). Responsibility for ensuring appointment attendance is then shifted to the staff in care home environments (770-773). Inadequate support is constructed as the more plausible explanation for non-attendance by giving an example from her own experience (773-779). Alison positions herself as fulfilling her own responsibilities (she phones up and has previously informed them about the appointment). Staff are positioned as inadequate; they are disorganised and so the appointment was forgotten despite a keyworker being present when the appointment was
made. The speech of the staff and her own thought processes are reported and acted out, adding the evaluative account that staff have failed in their responsibilities and expressing her frustration (776-779). The person with learning disabilities is positioned as in need of support from professionals (he is ‘very overweight’) and as playing a passive role; it is staff who are responsible for keeping track of appointments. As described further in section 6.4, inadequate support and non-attendance are constructed as constraints on the ability of the professional to provide quality care.

6.3.3 Repertoires of difference and disability

Like supporters, healthcare professionals positioned people with learning disabilities as different to people without learning disabilities in ways that impact on the diabetes appointment process and their diabetes care generally. Professionals drew on conflicting repertoires that they were responsible to provide quality care by acknowledging and adapting to these differences and that treating someone differently due to their learning disabilities can be problematic.

6.3.3.1 Professionals as responsible to adapt to differences to ensure good care

A common way in which people with learning disabilities were constructed as different to other people with diabetes was in their cognitive abilities; particularly their ability to understand information. Professionals described themselves adapting their communication to suit the level of understanding and learning style of people with learning disabilities.

Alison explains how she communicates with people with learning disabilities.

**Extract 11**

405 Alison: Well definitely um try and use well trying to understand
406 it’s no good me writing things down if they can’t read um
407 so trying to understand obviously if their keyworkers
408 there as well trying to get from their keyworker what
409 would - well trying to get from them both you know what
410 would be the most useful way really. ...
so very much trying to talk about - keep it simple, talk
about actual foods really and just and then trying to
negotiate with them as I would with anybody not just tell
them but try and negotiate what they feel they can do
and just make some very very simple goals, maybe just
one or two simple goals to be working on.

(Alison, line 405-416)

As described in section 6.3.1 people with learning disabilities are positioned in an active
role as Alison describes ‘trying to negotiate with them as I would with anybody’ (412-414). People with learning disabilities are constructed as different in their learning style (405-411) and in their ability to work on goals (415-416). Alison positions herself as responsible to find out the best way of informing the individual (405-410) and adapting her education style through use of pictures, simple concrete examples and a limited number of simple goals (415-416). The person themselves and keyworkers are positioned as having better knowledge of the individual (407-410), which Alison can make use of to target her communication style ‘trying to get from them both you know what would be the most useful way really’ (409-410). People with learning disabilities are constructed as able to understand and engage; they can learn and negotiate but as the professional Alison is responsible for conveying the information in an appropriate way.

6.3.3.2 Difference as problematic

Professionals occasionally drew on the idea that assuming difference or incompetence because someone has learning disabilities is problematic since all people with learning disabilities are not alike. Within this repertoire, people with learning disabilities were positioned as a heterogenous population.

Extract 12

Dr Jones: ...I think er we could perhaps have er systems that are
bespoke er I guess the - and the materials that are
bespoke. I guess the challenge of that in general practice
During a narrative on ways to improve diabetes care for people with learning disabilities, Dr Jones raises the possibility of bespoke systems, something his practice does not currently have. The subsequent narrative works to construct the theoretical bespoke system as problematic by making use of contrast structures (Potter & Wetherell, 1987; Potter, 1996). Bespoke systems are more likely to go wrong (374-377) whereas, systems that apply to everyone (like the current system) are constructed as relatively reliable: ‘people don’t fall through the net so much’ (375-377). At lines 379-380, the possibility of making care ‘a bit more individualised’ is raised again but immediately questioned (380-384). Theoretical changes that aim to make care more ‘individualised’ are constructed as risky; since people with learning disabilities are not the same as each other (380-384), assuming difference in competence (the need for support during the consultation) and treating all people with learning disabilities as different from anyone else with diabetes simply on the basis of their disability may result in care that is less person-centred and causes offence (384). Dr Jones therefore attends to the idea that bespoke/individualised care may be of better quality to his practice’s current system but builds a case against this by questioning the value of bespoke systems and implicitly constructing the existing state of affairs as preferable.
Summary

People with learning disabilities were constructed as active patients who have a responsibility to play a role in their diabetes care. Since people with learning disabilities are positioned as different in their competence to fulfil this responsibility, professionals and family and paid carers were positioned in a supporting role. Professionals constructed themselves as having a responsibility to ensure their care is adapted to the needs of people with learning disabilities, such as taking a different approach to communication. In contrast, treating people as different due to their learning disability was sometimes constructed as problematic and likely to be unsuccessful.

6.4 Quality is constrained

All participants drew on the idea that the quality of appointments and diabetes care generally for people with learning disabilities is constrained by factors outside of their control as healthcare professionals. This is reminiscent of ‘practicalities talk’ previously identified by discourse analysts (Potter & Litton, 1985; Wetherell et al., 1987) and discussed earlier in section 6.2. As found in previous discourse analysis of accounts about people with learning disabilities, participants described a mixture of internal/individual and external/environmental obstacles to quality care (Jingree & Finlay, 2008; Wilcox et al., 2006). Within this repertoire can be seen the recurring idea that lack of success in achieving care processes or improving outcomes was not due to lack of effort on the part of the professional. In this way, participants were able to describe care that did not achieve improvements whilst constructing a positive professional identity.

6.4.1 Quality as limited by rules

All participants referred to the idea that diabetes primary care is subject to rules that can act as barriers to tailoring appointments to the needs of the individual. Sometimes participants constructed these rules as unchangeable with professionals positioned as powerless. At other times rules were constructed as flexible with the professional ‘bending’ the rules to make care more effective.
Amanda explained that although she found home visits particularly valuable for people with learning disabilities, new rules now restrict professionals in her role to seeing people within the primary care practice.

**Extract 13**

499 Amanda: Um I used to I actually used to visit people at home but um they sort of changed the rules so we don’t we don’t do home visits now.

502 Interviewer: Oh okay right.

503 Amanda: I mean the doctors do but the nurses - I don’t know if that’s something to do with funding or something, something silly. Um when I was a community diabetes nurse obviously I did visit people at home so then you’ve got a much better understanding of the environment that they live in and you know if they’ve got – if they’re neglecting themselves you can refer to the various care agencies, district nursing or if you’re worried about the person so yeah you get a much better picture when you visit them at home definitely but obviously here you’ve just got a snapshot...

(Amanda, line 499-513)

The rule against home visits is constructed as unreasonable and unwise. A potential justification of the rule is suggested (‘funding’) but Amanda aligns herself away from the view that this is reasonable ‘or something silly’ (503-505). Description of external obstacles in accounts of people with learning disabilities has been described as a ‘context discourse’ (Wilcox et al., 2006). A strong case is built for the benefits of visiting people in their own homes (506-511) using evidence from her experience as a community nurse (you understand their environment and can tell if people are neglecting themselves). This is contrasted to the more limited clinical setting which just gives ‘a snapshot’ (512-513). The suggestion that people may be ‘neglecting themselves’ or giving cause for concern positions people with learning disabilities as potentially vulnerable and so possibly in need of home visits (508-511). In this instance, the rules put Amanda in a powerless position since they
prevent her from conducting consultations in the home despite her construction of home visits as more effective.

At other times, rules were constructed more flexibly. The ways in which participants described ‘bending the rules’ included giving additional and longer appointments and not discharging people who do not attend. Alison is an advanced dietician who works both within primary care practices and the community. Below, she contrasts the flexibility of her role with the limitations faced by her colleagues whose roles restrict them to primary care clinic settings with their rules and systems.

**Extract 14**

366 Alison: ...I can do home visits I’m quite you know flexible with my time but I can imagine if someone say if they were just on metformin and that they’re type two and that wouldn’t get triaged to me so it might be like a another band a band five dietician so they’d probably end up seeing someone in clinic with a thirty minute appointment who might come with or without their keyworker

367 Interviewer: Mmmm

368 Alison: so you know you can still do something but that would be more limited and then it would be sort of three three appointments probably and then that’s it...

370 Again I would probably you know I’ll bend the rules (laughs) you know a lot probably put a bit longer in if I feel that’s necessary.

371 Alison, line 366-379)

Making use of contrast structures (Potter & Wetherell, 1987; Potter, 1996), Alison positions other healthcare professionals as limited by rules to a specific amount of time and to the clinic setting (370-378). Care bound by these rules is constructed as inflexible and possibly inadequate because although you can ‘still do something’ the person may not come in with their keyworker and length and number of appointments is limited (371-372, 375-376). In comparison, Alison positions herself as flexible; she is not constrained but will ‘bend the rules’ and ‘put a bit longer in if I feel that’s necessary’.
6.4.2 Quality as limited by available resources

All healthcare professionals drew on the repertoire that the quality of the care that they provide is limited by resources such as time, support, money, and accessible resources. People with learning disabilities were often constructed as different in their need for more time. Like Alison in the example above, participants sometimes positioned themselves as flexible and not allowing time to be a constraint. In contrast, three participants constructed making more time for patients with learning disabilities as problematic as seen in the extract from Hilary.

**Extract 15**

515 **Hilary:** Mmm well every patient is an individual and there are no hard and fast rules at all but I think our aim is to provide equal care for people with learning difficulties, that’s our aim you know to give as much as we can um and you need to be prepared to give more time um within reason because if too much time is taken up my time is taken up looking after him something else is gonna have to go you know children aren’t gonna get their vaccinations and you know people with cancer aren’t gonna get their Zoladex injections so it has to be tailored and it has to be realistic you know.

(Hilary, line 515-525)

Giving more time to people with learning disabilities is initially provided as an example of good care (518-520). People with learning disabilities are constructed as different in their need for more time and professionals need to ‘*give as much as we can*’ and be ‘*prepared to give more time*’. Stating ‘*that’s our aim*’ may act as a disclaimer (Hewitt & Stokes, 1975) before describing practical constraints on achieving that aim. The feasibility of giving more time is then questioned with more time downgraded to ‘*within reason*’ (519-525). Time is constructed as a limited resource using examples of how particularly vulnerable groups (children and people with cancer) may suffer if too much time is given to a person with learning disabilities. This shows similarities to the constructions of some difficulties as reasonable by participants with learning disabilities. A practice/principle discourse
(Wetherell et al., 1987) can be seen here; care ‘has to be tailored’ which may involve more time but ‘it has to be realistic’ and ‘within reason’. There is also a suggestion that care is unequal if people with learning disabilities are given more time than other people (521-525). This draws on discourses of ‘fair shares’ (Wetherell et al., 1987).

Day-to-day support for people with learning disabilities was also often constructed as a limited resource. This restricts the ability of professionals to improve the diabetes of the individual since the person does not have support to put advice from the appointment into practice. Linda constructed the amount of support given as insufficient to ensure a healthy diet.

**Extract 16**

146 **Linda:** ... I will write it out ((action plan)) for them or I will email manager and she likes it in writing because then she can go back to social services and say they need more support.

150 **Interviewer:** Yes

151 **Linda:** It doesn’t work they usually say no

152 **Interviewer:** Right

153 **Linda:** unfortunately and we’ve tried very hard with a couple of patients to – because their diet was just appalling you know and they were just eating everything they shouldn’t have and you know because nobody was guiding them they didn’t know, they didn’t have an awareness that actually this food tastes nice I shouldn’t eat it um

... 

170 **Linda:** Mmm. It’s because they’re limited to a certain amount that some manager has decided not – the local managers are good it’s actually the next step up who will agree how much funded extra support they can have.

(Linda, line 146-173)
Linda builds a strong case that support with diet is necessary (153-158); people have an ‘appalling’ diet but lack the awareness and ability to eat healthily without support (146-149). This removes responsibility for improving diet from people with learning disabilities themselves. This view is supported by the care home manager (147). Linda positions herself and the care manager as making efforts to resolve the problem (146-149). Support is constructed as an insufficient resource restricted by social services and unknown authority figures who decide funding ‘some manager has decided’ (170-173). Despite her efforts, changing this decision by anonymous powerful others is constructed as beyond Linda’s control. The idea that health is dependent on factors beyond the control of healthcare professionals is familiar in the literature (Powrie, 2003). Linda draws on the idea that support is dependent on individual ability as identified in previous research (Fullana et al., 2019). However, the constraint of unavailable funding is constructed as external, drawing on a ‘context discourse’ of obstacles (Wilcox et al., 2006). This performs identity management; Linda cannot do more to improve diet if people with learning disabilities lack the ability to manage unsupported - but sufficient support is unavailable. In this way responsibility for consistently poor diet in some people is positioned firmly away from the professional, defending against any potential accusation of failure by the professional to improve diabetes care.

6.4.3 Learning disability as a constraint

Within repertoires of quality of care as restricted, professionals commonly constructed learning disability itself as constraining quality of diabetes care. The characteristics of this population or specific individuals due to their learning disabilities were constructed as limiting what could be achieved during and outside the appointment. As seen in section 6.2 characteristics of people with learning disabilities were sometimes described as making care processes less achievable. Additionally, having learning disabilities was constructed as restricting the ability of professionals to successfully convey information about diabetes and lifestyle since the person is less likely to understand or be receptive.

Linda describes her progress with one person with learning disabilities as constrained by unwillingness to cooperate and ‘naughty’ behaviour.
Extract 17

277 Linda: ...She’s she’s naughty, she’ll say ((changes voice)) ‘I’ve been told I have to I have to eat lots of food with my diabetes’ and she’s, she’s this shape ((mimes round shape)) okay

280 Interviewer: Yes yes

281 Linda: so and she’s er she’s well able to do things if she wants to but she can be really difficult so she’s quite complicated and we’ve tried loads of things with her drugs wise and she says oh all of them disagree with her and she can’t take them and so it’s she she’s hard work ... she just she just plays up basically like a toddler and that’s exactly what she does she behaves just like a toddler ((changes to child-like voice and bangs fist on desk)) ‘I want I want and I’m not having that’ and she’ll scream and shout at you and be really difficult so.

(Linda line 277-291)

Here, successful diabetes care is limited by the person’s uncooperative behaviour. The person with learning disabilities is not positioned as lacking ability since she is ‘able to do things if she wants’ but is positioned as challenging in her behaviour and emotional competence. Linda describes her as ‘naughty’, ‘difficult’, ‘complicated’, ‘hard work’ and ‘like a toddler’ and constructs her as unreliable (277-280) and uncooperative (285-291) in her diabetes care. Reporting and acting out the child-like speech and behaviour (288-290) strengthens her account (Seymour-Smith, Wetherell, & Phoenix, 2002) and adds an evaluative element (Bakhtin, 1981, as cited in, Maybin, 2001). Learning disability is constructed as an internal and unalterable obstacle, drawing on an ‘individual pathology discourse’ (Jingree & Finlay, 2008; Wilcox et al., 2006). A strong case is built that despite their efforts ‘we’ve tried loads of things with her drug wise’ (284-287), professionals are constrained by characteristics of the individual with learning disabilities that make it difficult or impossible for guidance on quality diabetes care to be successfully communicated and put into practice.
Summary

Quality of appointments and diabetes care generally were constructed as constrained by issues outside of the control of healthcare professionals. Some of these were constructed as open to change by ‘bending the rules’ but more often they were constructed as persistent inflexible barriers. Constraints included rules, limited available resources and characteristics of people with learning disabilities. This repertoire was often drawn on to explain poorly controlled diabetes in people with learning disabilities and professionals positioned themselves as making efforts that were constrained by these barriers outside of their control.

6.5 Repertoires of knowledge

Like supporters, professionals drew on repertoires of knowledge when constructing quality appointments. All stakeholders were positioned as having some form of knowledge. However, professionals were more regularly positioned as having the right kind of knowledge to make good diabetes care decisions. When drawing on this repertoire, participants positioned people with learning disabilities in potentially conflicting ways: as passive recipients of care from more knowledgeable others and as having sufficient understanding and capacity to make their own choices.

6.5.1 Professionals as knowledgeable decision-makers

Unlike supporters who distinguished between the medical knowledge of professionals and the experiential knowledge of supporters, all healthcare professionals positioned themselves as having both good medical knowledge and understanding of the individual gained through experience.

Dr Jones explains how his knowledge of one long-term patient informs his approach to her care.
Extract 18

95  Dr Jones:  ... but I’ve known her for many many years um and er so
96  yeah I’ve got a reasonably good relationship with her and
97  I think I know more of the background of what’s going on
98  and I think my one of my main roles with her is to um
99  avoid over investigating and over referring about every
100  issue that comes up and that’s the advantage of having
101  seen someone over many years is that you don’t um over
102  and inappropriately respond to each er issue.

(Dr Jones, line 95-102)

Dr Jones positions himself as having good experiential knowledge of the person with
learning disabilities (95-97, 100-102). Using this knowledge of the person and her
background informs his decision-making. There is an implication that this person is likely to
raise many and perhaps minor issues (98-100). The knowledge that he has gained of the
person over ‘many years’ informs his ‘role’ and decisions not to ‘over and inappropriately
respond’ (98-102).

Linda discusses the decision to use appetite suppressing medication for one person with
learning disabilities.

Extract 19

724  Linda:  ...I think it’s trying to give them person specific treatment
725  so bearing in mind that some of them aren’t gonna be
726  able to test their sugars very often and yet their sugars
727  are going up. We need to be finding medication that is
728  actually not gonna cause too many side effects

729  Interviewer:  Right

730  Linda:  so this chap who’s having an injection once a week that’s
tailored to him and it’s opened my eyes to long term very
732  overweight diabetics um for whom we can do quite a lot
733  in trying to encourage them with diet but we’re not
winning but if we give them something that suppresses their diet – their their appetite

Interviewer: Oh I see

Linda: and helps them lose weight we’re winning it, we’re ticking a few boxes

...\n
Linda: Um and I think for others who are very overweight that’s very tailored diabetic care because I don’t want them on insulin because I think the risks are too high whereas this drug does not give them hypos.

Interviewer: Right, do you think that is worse if you’ve got a learning disability?

Linda: Yeah yeah because they’re not gonna test, they’re not gonna tell you and they might not know how to take medication.

(Linda, line 724-759)

Linda positions herself as the person best qualified to judge the risks and benefits to make the best medication related decision. The combined knowledge of medication side effects (hypoglycaemia) and traits of people with learning disabilities (difficulty testing blood sugar levels and managing hypoglycaemia) inform her decision not to use insulin (724-728, 752-759). Furthermore, her knowledge of people with learning disabilities generally and this person specifically is that methods of controlling diet to manage weight or balance blood sugar levels other than medication are unsuccessful (733-735). The decision to use an appetite suppressing drug is informed by Linda’s knowledge of the person and so is ‘person specific’ and ‘very tailored diabetic care’, drawing on wider healthcare discourses that care should be person-centred (National Institute of Health and Care Excellence (NICE), 2015). Describing what ‘we’ should do (727-728, 734-738) and what ‘I’ ‘want’ and ‘think’ (751-755), Linda and professionals generally are positioned as responsible for taking decisions about diabetes care ‘I don’t want them on insulin because I think the risks are too high’. People with learning disabilities are implicitly positioned in a passive role, similar to
previous observations of people with learning disabilities positioned as passive with ‘experts’ making overall decisions about their lives (Fullana et al., 2019).

One person drew on the idea that assessments can be conducted without consent if in the best interests of the individual. In this case the right to choice is not constructed as a constraint on what the professional can achieve. Hilary discusses the idea of consent in relation to blood tests for one person with learning disabilities.

**Extract 20**

<table>
<thead>
<tr>
<th>Line</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>308</td>
<td>Hilary: I think well if you haven’t got consent, if you wanted to</td>
</tr>
<tr>
<td>309</td>
<td>get consent then he would’ve died a long time ago. We</td>
</tr>
<tr>
<td>310</td>
<td>have to go beyond that and think you know well what’s</td>
</tr>
<tr>
<td>311</td>
<td>the best interest and his family wanted us to treat him,</td>
</tr>
<tr>
<td>312</td>
<td>how could he consent you know he he doesn’t have the</td>
</tr>
<tr>
<td>313</td>
<td>ability to give consent, the physical ability of consent you</td>
</tr>
<tr>
<td>314</td>
<td>know but I wouldn’t force him I’d just give up that day</td>
</tr>
<tr>
<td>315</td>
<td>and try again...</td>
</tr>
</tbody>
</table>

(Hilary, line 308-315)

Here the professional is positioned as knowledgeable about the person’s best interests. The person with learning disabilities is constructed as a passive recipient of care since ‘he doesn’t have the ability to give consent’. The extreme case formulation ‘he would’ve died a long time ago’ is used to construct the alternative of not acting as dangerous. The supportive consensus of the family (‘wanted us to treat him’) was brought in. If the person lacks ability to consent then the professionals and family have the knowledge to work in ‘the best interest’. At line 314-315, Hilary defends against the idea that she forced treatment/assessment on the individual, but would ‘try again’ another day. The idea that enforcing treatment is wrong is thus attended to by raising a practical barrier to gaining consent and building a case that it is in the person’s best interests.

6.5.2 The role of supporters – contextual knowledge

Supporters were sometimes constructed as having good knowledge of the individual they supported and their day to day care. Unlike supporters themselves, professionals did not
equate supporter experiential knowledge with superior decision-making about effective
day to day diabetes care. Instead, they were positioned in a supporting role, clarifying facts
during appointments and reinforcing advice from professionals in the home environment.

Dr Jones describes family and paid carers as improving the level and accuracy of
information during consultations.

**Extract 21**

188 Interviewer: So how is it helpful if they bring someone with them?
189 Dr Jones: Um because I think the er the er the nature of the
190 information is um better so I think you get er - so I ask a
191 question ‘how are you and have you had any hypos?’ and
192 ‘no no I’m fine’ and then the the family member or the
193 keyworker will say ‘well you did have that’ so um I think
194 there are aspects of recall about what’s happening. Um
195 some of the background like about how how and when
196 medication is taken
197 Interviewer: Right
198 Dr Jones: things like their dosset boxes or whether it’s with meals
199 or whatever so some of that information you can get
200 from other people. When you’re then making action
201 points and deciding what should be done um having two
202 people in the room is better than one cause patients only
203 - patients without learning disabilities remember three
204 things from a consultations so if you’ve got two people
205 that helps.

(Dr Jones, line 188-205)

In line with the repertoire that people with learning disabilities are the patient (section
6.3.1) people with learning disabilities are described as taking an active role in the
consultation (questions are directed to the person) (191-192). However, they are
positioned as lacking the competence to reliably remember and report information about
their daily diabetes management (192-194). They are also even less likely than other people with diabetes to remember their consultation (201-205). Use of reported speech demonstrates the difference between the knowledge of the person with learning disabilities and the supporter (192-193) and adds authenticity to the account (Wertsch, 2001). The supporter prompts and provides additional and ‘better’ contextual information on daily diabetes care ‘the nature of the information is better’. This implicitly positions supporters as more competent in their ability to remember and provide accurate and ‘better’ quality information to the doctor in terms of ‘background’ knowledge of daily management of the condition (medication and meals) (195-196, 198-200). Decision-making is constructed as a shared effort (200-202) but the role of the supporter is focused on helping the person remember action points after the consultations (203-205). As seen in the chapter on people with learning disabilities, supporters are placed in a supporting, back-up role. Although supporters were often constructed as having good contextual knowledge of daily diabetes care, two participants positioned supporters as lacking knowledge of diabetes and so hindering good care, including poor knowledge of why the appointments are important, keeping track of appointments (as in extract 8, section 6.3.1) and how an individual’s diabetes is being managed.

Extract 22

346 Alison: I have done a teaching session there (supported living environment)) as well because people get people get very confused, especially if they’ve got someone with type one and type two it’s completely different the treat - you know type one is gonna be carb counting and type two is more likely to be a healthy diet and doing some exercise so people get really really confused about what’s best for that person.

354 Interviewer: Yeah yeah do you find staff have much knowledge of diabetes?

356 Alison: Erm well so not very - yes but limited and usually quite confused and not always correct as well...

(Alison, line 346-357)
Alison describes the diabetes knowledge of support staff within supported living environments as ‘confused’ and inaccurate. Describing the different approaches needed for different types of diabetes constructs this confused knowledge as dangerous and potentially poor care because confusion about the different types of diabetes could lead to the wrong type of treatment (348-353). In contrast, Alison has diabetes knowledge and positions herself in an educating role (346-347). It is not that staff have no knowledge, but the knowledge that they have is ‘confused’ and ‘not always correct’. People with learning disabilities are not positioned as having a role here, implying a dependence on staff knowledge.

6.5.3 Knowledge and people with learning disabilities

In common with supporters, participants sometimes positioned people with learning disabilities as entitled to choice and independence in their diabetes care. As can be seen throughout this chapter people with learning disabilities were constructed as having varying levels of knowledge and understanding. Despite positionings of people with learning disabilities as having limited, unreliable or inconsistent knowledge they were sometimes positioned as having the kind of knowledge that demonstrates capacity and entitles them to make decisions about their diabetes care. Although participants did not describe formal assessments of mental capacity, informal views on capacity were sometimes referenced.

Alison describes the difficulty of improving concerning diabetes care for one person with learning disabilities but constructs the person’s capacity as limiting the ability of others to intervene.

**Extract 23**

265 Alison: ... there’s been sort of talks about you know do they need
266 to um do a mental capacity and do they need to sort of
267 restrict her

268 Interviewer: Yes
269 Alison: um but I you know ((Diabetes Specialist Nurse)) and I feel that because I had done this education session at the beginning I felt actually her knowledge was quite good and ((Diabetes Specialist Nurse)) and I have plenty with people with diabetes who don’t do what they should do and you know eat absolutely loads and you know whole cake at a time or you know a whole tub of ice cream well we don’t you know we let them carry on don’t we so you know (laughs).

Having described consistently problematic diabetes management for one person with learning disabilities, Alison raises the possible solution of staff restricting the individual’s dietary choice (265-267). This would require professionals to formally assess the person’s capacity ‘to do a mental capacity’. The need for formal assessment is discounted since the person is positioned as having capacity based on Alison’s own knowledge that the person has received diabetes education and Alison’s own impression of her knowledge ‘I felt actually her knowledge was quite good’ (269-271). The Diabetes Specialist Nurse is brought in to give expert supportive consensus to this view (269-271). Since this person has capacity, she is positioned as no different from ‘plenty’ of people with diabetes who make unhealthy choices and are not restricted (272-277). Making an unwise choice is therefore not specific to people with learning disabilities. This positioning of the person as knowledgeable and similar to other people with diabetes constructs restricting her on the basis of her learning disability as contrary to her rights (273-277). The positioning of capacity is based on informal assessment that nevertheless draws on ideas from the Mental Capacity Act; capacity is assumed and the right to choice is contingent on knowledge and understanding. The people who have made this informal assessment are professionals who have experiential knowledge of the individual.

Again, the idea of quality care as constrained can be seen as the Mental Capacity Act and the person’s understanding means that it is not possible to intervene in their dietary choices in order to improve their diabetes management. This is similar to supporters in the previous chapter, for example Karen, who sometimes position themselves as unentitled to intervene in unhealthy dietary choices because the person has understanding of what is good or bad for them. Similarly, people with learning disabilities sometimes constructed
themselves as competent and knowledgeable to make complaints about infringements on their independence and choices (for example, Lynne).

Summary

Professionals positioned themselves as having both experiential and diabetes care knowledge, enabling them to make informed and appropriate decisions about diabetes care for people with learning disabilities. Supporters were positioned as having valuable contextual knowledge allowing them to support the professional understanding of the person and the person's knowledge of advice at home, but they were not positioned as decision makers. Knowledge of both supporters and people with learning disabilities in relation to diabetes were questioned and constructed as unreliable. Nevertheless, the knowledge of people with learning disabilities was constructed as sufficient to confer capacity and therefore entitlement to make unrestricted decisions in relation to their diabetes care.

6.6 Conclusion

In common with participants in the previous data chapters, healthcare professionals discussed a variety of experiences in their consultations with people with learning disabilities. In contrast to people with learning disabilities and their supporters, professionals rarely constructed their own practise as inadequate but rather as having varying levels of success in achieving their goals.

In line with supporters and participants with learning disabilities, healthcare professionals drew on a number of other key ideas in order to construct the quality of diabetes care appointments. These included: that diabetes care appointments have purposes that should be achieved and that all stakeholders have roles and responsibilities that should be fulfilled. Like supporters, professionals sometimes made use of repertoires of knowledge and drew on the idea that people with learning disabilities have a right to choice.

Some differences were also apparent in the pervading interpretative repertoires and subject positions used by healthcare professionals compared to other participants. A
common repertoire drawn on by professionals was that the quality of appointments and diabetes care generally is constrained by obstacles beyond the primary care practitioner’s control. Therefore, lack of improvement in diabetes care, failure to attend appointments and unsuccessful attempts to complete care processes were rarely attributed to inadequate care.

Dilemmatic repertoires were present on the importance of achieving the same care processes recommended for all people with diabetes and the importance of prioritising experience over the achievement of care processes for people with learning disabilities. Making use of practice/theory rhetoric and flexibly drawing on conflicting positionings of people with learning disabilities as the same and different from anyone with diabetes, the meaning of quality diabetes care for this population was flexibly constructed to avoid accusations of inadequate or inequitable care.

Chapter 7. Discussion

7.1 Overview

This research aimed to improve understanding of the social construction of ‘quality care’ in relation to diabetes primary care appointments for adults with mild-to-moderate learning disabilities. As described in the literature review chapter, a particular gap in our understanding of diabetes care appointments for this population is that despite calls to improve quality of health care for people with learning disabilities, what is meant by ‘quality’ diabetes care appointments for this population remains unclear. Primary care appointments are of priority for research since these encounters are an important point of contact between people with diabetes and healthcare professionals and some studies have questioned the quality of primary care diabetes appointments for adults with learning disabilities (Glover & Evison, 2012; Shah et al., 2006). This project therefore aimed to explore how key stakeholders (adults with mild-to-moderate learning disabilities and diabetes, those who support their diabetes management and healthcare professionals) discursively construct quality diabetes care appointments including responsibility for quality care during accounts of the experience of diabetes care appointments.
Data analysis identified the key interpretative repertoires drawn on by each stakeholder group to construct the concept of quality in relation to primary care diabetes appointments and the ways in which speakers positioned themselves and others within these repertoires. Dilemmatic repertoires and positionings were found within accounts and the rhetorical devices which functioned to manage the resulting ideological dilemmas were also considered. In line with findings from previous projects taking a social constructionist perspective, ‘quality care’ was found to be a fluid and changeable concept within these accounts that was flexibly and purposively constructed in talk (Aldousari, 2015; Edwards, Staniszewska, & Crichton, 2004; Walshe, Nagington, & Luker, 2013).

This chapter will examine findings on the main interpretative repertoires and subject positions drawn on by participants to construct the concept of ‘quality care’ in diabetes primary care appointments for adults with mild-to-moderate learning disabilities. Relevance to the existing literature on diabetes care and people with learning disabilities and the literature on the discursive construction of learning disability and diabetes care will be considered. The ways in which my PhD research contributes to our understanding of discursive devices and their functions in relation to these topics will also be discussed.

A further aim of this project was to explore similarities and differences in the ways that different stakeholders construct quality diabetes care for adults with learning disabilities. This chapter will describe and explore possible reasons for and functions of similarities and differences in the discursive resources commonly drawn on by different stakeholder groups. Implications of the available and dominant discursive repertoires and ways in which they were managed for quality diabetes primary care for this population will then be considered.

7.1.1 Socially constructing quality diabetes care appointments for adults with learning disabilities

Like previous research on the social construction of quality care (Aldousari, 2015; Nagington et al., 2016; Walshe et al., 2013), the present study found that multiple and sometimes conflicting versions of quality care were constructed, drawing on socially available resources. In line with previous findings, (Annandale & Hunt, 1998; Blumenthal, 1996; Campbell et al., 2000; McGlynn, 1997), what constituted quality in terms of diabetes
care appointments for speakers varied between participants, stakeholder groups and within the same account. Three repertoires were commonly drawn on by participants from all three stakeholder groups: i) that diabetes primary care appointments have particular goals that are successfully achieved in good quality care; ii) that all stakeholders have roles and responsibilities in relation to appointments and that quality can be assessed according fulfilment of these roles and responsibilities; iii) that stakeholders have varying types of knowledge and understanding relating to an individual’s diabetes care and that knowledge is important in determining the effectiveness of primary care encounters. There were areas of difference in the ways that members of different stakeholder groups constructed quality drawing on repertoires around: the entitlement of people with learning disabilities to independence and choice; the reasonableness of appointment difficulties and the idea that quality of care is constrained. The repertoires described were not separate within speakers’ accounts but interconnected and combined to support multiple constructions of quality care. Participants’ constructions of quality care performed numerous functions within talk including managing identity, apportioning blame or credit for poor/good experiences and justifying different/inequitable care.

Within these repertoires all stakeholders were positioned in varying and often conflicting ways. People with learning disabilities were positioned as: independent, competent, human, legally entitled, possessing capacity, proactive, knowledgeable and responsible. They were also positioned as dependent, passive, lacking (cognitive, social or emotional) competence, vulnerable, child-like, difficult and irresponsible. Supporters were positioned as knowledgeable, competent, upholders of rights, and responsible, as well as incompetent, unnecessary, restrictive and powerless. Healthcare professionals were positioned as knowledgeable, professional, empathic, conscientious, competent and as restricted/constrained, powerless, incompetent, and pragmatic. Different positionings were presented to support different constructions of quality care. For example, where people with learning disabilities were positioned as competent and proactive good quality care promoted their involvement, independence and choice relating to diabetes care appointments. On the other hand, where people with learning disabilities were positioned as lacking competence, dependent and unreliable, good quality care took control or provided support with appointment related tasks.

There were therefore conflicting ideas and positionings present in constructions of quality diabetes care. Three particularly prevalent discursive devices were made use of to negotiate varying versions of quality and to manage dilemmatic repertoires and
positionings within accounts. These were: i) categorisation, ii) use of practice/principle rhetoric and iii) the construction of empowerment/independence for people with learning disabilities as bounded. Section 7.4 will consider how the present study furthers our knowledge of these discursive practices and the implications of the ways these discursive devices were used on the quality of diabetes care for people with learning disabilities.

7.1.2 Similarities and differences in the construction of quality care by different stakeholders

One aim of this study was to explore similarities and differences in the discourses of key stakeholders when considering quality primary care appointments for people with learning disabilities. Participants with learning disabilities, supporters and healthcare professionals drew on some similar discursive resources and rhetorical devices when constructing quality care. However, in common with previous research into the social construction of quality care (Aldousari, 2015; Walshe et al., 2013), the present study found some distinctions in the ways that different stakeholder groups constructed quality in relation to diabetes care appointments and the dominant discourses that were drawn upon.

To construct quality care, participants drew on similar ideas that: quality depends upon achievement of appointment aims, quality is dependent on stakeholder fulfilment of roles and responsibilities, and quality is dependent on knowledge. Although these three repertoires were common to all stakeholder groups, there was some variation in the dominance and function of these repertoires. This chapter will begin by considering repertoires common to all stakeholders and will highlight differences in the use of these common repertoires by members of different stakeholder groups. Repertoires relating to the promotion of independence, quality as constrained and repertoires of difficulty were drawn on by specific stakeholder groups and rare or absent in the talk of other stakeholders. Section 7.3 will focus on two of these differential discourses.
7.2 Repertoires common to all stakeholders

This section discusses three repertoires that were commonly drawn on by participants from each stakeholder group when constructing the quality of diabetes care appointments. Specifically: i) that appointment quality is dependent on achievement of goals; ii) that quality care can be assessed according to whether key stakeholders fulfil roles and responsibilities; and iii) that knowledge is important in determining the effectiveness of primary care encounters.

7.2.1 Appointment quality is dependent on successful achievement of appointment aims/purposes

The literature on quality diabetes care for people with and without learning disabilities assesses quality care according to the achievement of quality standards set out by organisations such as Diabetes UK and NICE. In this study, all stakeholders drew on the idea that diabetes primary care appointments have purposes and that quality of care can be judged according to whether these purposes have been successfully achieved. Appointment goals were variously constructed so that different and sometimes conflicting purposes were present within the same account. Ideas common to all stakeholders were that primary care diabetes appointments aim to: i) provide information about diabetes care in order to guide effective day-to-day diabetes management and ii) monitor the person’s diabetes through care processes. Occasions where these goals were not achieved (e.g. the provision of incomplete information) were sometimes presented by people with learning disabilities to construct appointments as inadequate whereas appointments that had improved the individual’s understanding of the condition were constructed as good (see chapter 4, section 4.1). Supporters drew less often on the idea that achieving the purpose of informing and monitoring determines quality care, but two supporters positioned healthcare professionals as blameworthy for providing incomplete information during appointments (For example, see chapter 5, section 5.4.3, extract 11). This idea was mirrored in the accounts of healthcare professionals who managed professional identity by building justifications of instances where these goals were not achieved (see chapter 6, section 6.2.3). These aims reflect current UK guidance on quality standards for diabetes care for adults, which state that care should include receipt of guidance and advice on
diabetes from healthcare professionals, and regular assessments/care processes to monitor diabetes care and screen for secondary complications (Diabetes UK, 2016a; Health and Social Care Information Centre, 2016a; NICE, 2016).

7.1.1.1 Care points as beyond the role of appointments

Conversely, appointment aims were sometimes constructed in ways which seemed at odds with UK guidance on quality diabetes care (aimed at all adults with diabetes). Notably, people with learning disabilities attributed responsibility for some care points outlined in the Diabetes UK *15 Healthcare Essentials* document (Diabetes UK, 2016a) and NICE guidelines (NICE, 2015a, 2016) to sources of support outside of the appointment setting (see section 4.1.3). Goals such as providing information and assessments were sometimes described as covered by sources of support outside of clinical encounters such as support workers. Other topics, which guidance describes as a marker of quality diabetes care (Diabetes UK, 2016a, 2019a; NICE, 2015b), were sometimes constructed as beyond the remit of diabetes primary care appointments and often as personal matters beyond the role of healthcare professionals altogether. These included discussion of pregnancy/sexual health, emotional wellbeing and referral to structured education programmes. Thus, an appointment did not need to meet recognised quality care standards in order to be good quality if recommended care processes were constructed as outside the appointment’s purpose or within the role of other sources of support. For example, people with learning disabilities described receiving dietary advice from support workers, having blood pressure and weight measured at supported living environments and dealing with emotional matters through self-reliance or by turning to family.

Neglecting recommended topics or care processes during diabetes appointments has previously been described as cause for complaint (Care Quality Commission, 2016) and a marker of inadequate care (Taggart et al., 2012). It is possible that some matters were constructed as beyond the remit of primary care diabetes appointments (and not cause for complaint) in this study because participants with learning disabilities had limited experience of these topics being raised during diabetes care appointments. Previous research has reported that diabetes appointments for the general population do not sufficiently cover psychological health (Care Quality Commission, 2016; Diabetes UK, 2008; National Health Service, 2010). Furthermore, people with learning disabilities are less likely to be referred to structured education programmes (Care Quality Commission, 2016) and
healthcare professionals may have difficulty discussing sexual health and pregnancy with this population (Kehmann, 2005). It is noteworthy that some of the topics present in standard diabetes care guidance that were not described as within the role of appointments by people with learning disabilities (emotional health, pregnancy/sexual health, referral to structured education programmes) are also often missing from easy read diabetes guides aimed at this population (Diabetes UK, 2014b; EasyHealth, 2013; University of Leeds, 2015).

7.2.1.1 Appointment goals as the same or different

Supporters and healthcare professionals drew on conflicting constructions relating to the goals of diabetes appointments for people with learning disabilities. Appointments were constructed as having the same goals as for people without learning disabilities or as having adapted goals. Specifically, supporters and healthcare professionals constructed the goal of ensuring that the encounter was a positive, motivating and untroubling experience for people with learning disabilities. Healthcare professionals sometimes constructed appointments for this population as aiming to be ‘gentle’, ‘less health structured’ and excluding assessment where this conflicted with the aim of providing an untroubling experience. When constructing appointment goals as the same regardless of whether the person has learning disabilities, participants often appealed to ideas of entitlements, rights and equality. This reflects policies on improving health/diabetes care for people with learning disabilities (Department of Health, 2001b; Health Research Authority, 2017; NHS Improvement, 2018) and the existing literature which often assesses quality of diabetes care for this population according to equal receipt of care processes (Balogh et al., 2015; Public Health England, 2016b; Shireman et al., 2010; Taggart et al., 2012). Within this repertoire, taking a different approach to appointments because the individual has learning disabilities (e.g. diluting information/incomplete care processes) was constructed as inadequate. Participants drew on extreme case examples of the possible detrimental consequences of neglecting the usual procedures and on the idea that inequitable treatment is morally incorrect. Within this repertoire people with learning disabilities were positioned as the same as other people with diabetes (see section 7.4.3 for further discussion of categorisation). Healthcare professionals sometimes brought in guidance
such as NICE key care processes to give supportive consensus to their assertions that people with learning disabilities should receive the usual care processes.

In contrast, when healthcare professionals drew on the idea that appointments for this population have adjusted goals, the aim to ensure appointments are untroubling and focus on the person’s experience was prioritised over coverage of health/diabetes topics and the successful completion of care processes. This ‘less health structured’ approach was also reflected in descriptions by people with learning disabilities that appointments confirmed that they were ‘doing well’ and problematic test results were rarely discussed. Constructing an untroubling experience as a goal of diabetes appointments for this population may attend to previous reports that people with learning disabilities feel fearful, anxious, pressurised, frustrated, inconvenienced or distressed by diabetes care appointments (Cardol et al., 2012b; Care Quality Commission, 2016; Hale et al., 2011; Turner & Emerson, 2013). However, they do not reflect the limited existing guidance on diabetes appointments for people with learning disabilities. These documents note that it is necessary to consider phobias, fears and anxieties but recommend that healthcare professionals make reasonable adjustments to enable the successful completion of assessments such as blood tests and eye exams (Diabetes UK, 2019b; Kachika, 2017; Turner & Emerson, 2013).

7.2.1.2 Functions of repertoires on appointment purpose

Different constructions of appointment goals were flexibly and purposively drawn on. The achievement of care processes as an appointment goal is a dominant discourse in diabetes care. The idea that diabetes care quality can be assessed according to the completion of care processes is predominant in healthcare. It can be seen in the diabetes care quality guidelines for adults with diabetes (Diabetes UK, 2016a; NICE, 2016), and the literature on quality diabetes care for the general population (Diabetes UK, 2016d, 2016a; Health and Social Care Information Centre, 2011, 2016c; NHS Commissioning Board, 2012). It is also apparent in the guidance aimed at adjusting appointments for people with learning disabilities, which recommends reasonable adjustments to ensure achievement of recommended care processes (Kachika, 2017; Turner & Emerson, 2013). It is therefore unsurprising that completion of care processes/monitoring of diabetes was often
constructed as a purpose of diabetes care appointments. When healthcare professionals recount instances of diabetes care that do not successfully achieve all recommended care processes, they are therefore open to accusations of inadequate care. Justification and professional identity management were thus performed by drawing on positionings of people with learning disabilities as different and reframing the goals of their appointments to be consistent with these differences. If people with learning disabilities are constructed as uninterested in health-related details and likely to become distressed or be uncooperative during assessments, adequate appointments need to be less health focused and need not include all recommended care processes. This shows similarities to Silverman’s (1987) findings that in consultations with parents, healthcare professionals drew on a ‘demedicalised’ model of children with Down’s Syndrome (e.g. ‘they are happy’) to successfully argue for different healthcare goals for children with and without Down’s Syndrome (Silverman, 1987a). Appealing to social rather than medical constructions of an individual with disabilities therefore presents an effective and difficult to counter argument which can be used to justify inequitable goals in medical procedures.

7.2.2 Roles and responsibilities

Participants from all stakeholder groups drew on the overarching repertoire that everyone has roles and responsibilities in relation to diabetes care appointments and that quality care was dependent on fulfilment of these roles and responsibilities. People with learning disabilities were constructed as patients who should have at least some active involvement and responsibility in relation to their diabetes care appointments. Healthcare professionals and supporters were constructed as responsible to ensure that people with learning disabilities could fulfil this role by providing support and adjusting the appointment process, for example, to ensure that the person could access appointments and communicate with professionals. Despite the commonality of these repertoires, there were some differences in the repertoires on roles and responsibilities and the ways they were used by different stakeholder groups. People with learning disabilities more often constructed themselves as proactive patients with a responsibility to ensure their own involvement. Supporters and healthcare professionals more often emphasised the role of others in ensuring that the people with learning disabilities could be proactive patients.
7.2.2.1 People with learning disabilities as proactive ‘patients’

Participants from all stakeholder groups constructed people with learning disabilities as ‘patients’ who should be actively involved in their diabetes care appointments. This conferred on people with learning disabilities a responsibility to play an active role in their appointments with healthcare professionals and supporters were positioned as responsible to help them to fulfil this role. The idea that people with diabetes should be proactive in their diabetes care is in line with UK and international diabetes care policies of self-management in partnership with healthcare professionals (Colagiuri et al., 2011; Department of Health, 2001a, 2008; Roberts, 2007) and advice provided by diabetes charities (Diabetes.co.uk, 2016a; Diabetes.org.uk, 2016; Diabetes UK, 2016c). It also reflects the literature on diabetes care for this population, which argues for the supported involvement of people with learning disabilities in setting and discussing goals for self-management (Cardol et al., 2012b; Kachika, 2017). The construction of people with learning disabilities as proactive patients shows similarities to findings that people with diabetes in the general population construct autonomous identities, resisting positionings of dependence (Broom & Whittaker, 2004; Parry et al., 2006). Equally, people with learning disabilities often resist attributes of incompetence associated with the stigmatised label of ‘learning disability’ (Beart, Hardy, & Buchan, 2005; Finlay & Lyons, 2000; Rouse & Finlay, 2016).

Positioning people with learning disabilities as proactive patients performed several functions. For people with learning disabilities, drawing on this repertoire built a competent identity that avoided the stigma of the learning disability label. For healthcare professionals and supporters, it presented enlightened respectful identities allowing the speaker to attend to and distance themselves from the alternative approach of assuming incompetence (e.g. speaking over the individual). Presenting the position of patient sometimes functioned to shift responsibility for consistently poor management/outcomes away from supporters and professionals. For participants with learning disabilities and supporters, accounts of experiences in which the individual’s membership of the category ‘diabetes patient’ was not recognised or prioritised by healthcare professionals were also used to build complaint, questioning quality of care.
7.2.2.2 People with learning disabilities as passive patients

Speakers make use of categorisation to order the social world (Wetherell et al., 1987). An alternative way of constructing the category of ‘patient’ for people with learning disabilities was as passive, with healthcare professionals making decisions about diabetes care or supporters taking control of appointment related tasks. This was sometimes constructed as reasonable or necessary, particularly in the case of medication related advice from healthcare professionals and when the person was positioned as lacking competence. In common with previous findings (Fullana et al., 2019), people with learning disabilities sometimes positioned themselves as passive and healthcare professionals and supporters as knowledgeable decision-makers who take over or provide support in areas where they lack competence. The idea that people with learning disabilities should play a more limited and supported role in their appointments drew on categorisations of the individual as a ‘person with learning disability’ with attendant characteristics of incompetence, irresponsibility and unreliability. These attributes have often been identified in discourse analytic literature on the social construction of learning disability (Rapley, 2004). In cases where the person was positioned in a passive role in relation to their diabetes care, the categorisation of ‘person with a learning disability’ was prioritised over their categorisation of ‘diabetes patient’. However, occasionally the construction of people with learning disabilities as passive or dependent due to incompetence was challenged and used to make complaint about the quality of the encounter. One way this was done was by prioritising the categorisation of ‘diabetes patient’. For example, supporters were critical of assumptions of incompetence and people with learning disabilities sometimes complained about supporters taking over appointment related tasks.

The need to foreground the identity of ‘diabetes patient’ for an individual who has diabetes in the context of describing their diabetes appointments would seem an unusual thing to need to do. When describing the experience of people with learning disabilities the availability of the category ‘learning disability’ and its potential attributes of incompetence appear to open the usual entitlements of the category of ‘diabetes patient’ (e.g. that the Dr will speak to you) to question. The individual may belong to the category ‘patient’ and thus expected to be the focus of the appointments, to play an active role, have independence and take responsibility. On the other hand, the individual may belong to the category ‘person with learning disability’ and so assumed to be lacking in competence and unable to play a fully active or responsible role. These conflicting ideas were sometimes managed by
redefining the category of ‘person with learning disabilities’ to include specific competence (e.g. Hayley can communicate well with her doctor if she is not discussing a problem). Alternatively, the category of ‘diabetes patient’ was sometimes revised to incorporate the category of ‘learning disability’. Within this category the individual had the entitlements of a ‘patient’ to be spoken to directly and offered involvement and responsibility but with the understanding that these efforts may be unsuccessful. For example, the healthcare professional may need to communicate with the supporter for further/accurate information about the person’s diabetes care. This shows similarities to the idea that empowerment for this population is loaned by more powerful others (Dowson, 1997) and that concepts such as empowerment and responsibility are redefined when applied to adults with learning disabilities (Jingree & Finlay, 2008; Rouse & Finlay, 2016). In the present study, constructions of an alternative category for diabetes patients with learning disabilities performs identity work for supporters and healthcare professionals. It attends simultaneously to discourses of self-management and empowerment in healthcare policy and learning disability services and socially available positionings of incompetence for people with learning disabilities. Therefore, quality diabetes care was associated with people with learning disabilities playing an active role but what constituted a proactive diabetes patient for this population was flexibly constructed. It sometimes included making decisions, actively communicating with professionals and being involved in appointment arrangements. On the other hand, being a ‘diabetes patient with learning disabilities’ could simply entitle you to a ‘respectful’ request by a healthcare professional for permission before discussing your diabetes care with a supporter. These different definitions have very different implications for the level of involvement that the person with learning disabilities has in their appointments and diabetes care more broadly.

7.2.2.3 **Quality care adapts to the needs of the individual**

Positionings of healthcare professionals and systems as responsible for adapting appointments to the needs of the individual are consistent with NICE guidance that information on diabetes should be accessible to people with additional needs including learning disabilities (NICE, 2015a) and suggestions on reasonable adjustments to diabetes care for this population (Care Quality Commission, 2016; Diabetes UK, 2019c; Kachika, 2017; Pilling, 2014a; Turner & Emerson, 2013). Strikingly, when directly asked about
‘reasonable adjustments’ participants from all stakeholder groups were unable to give examples and did not explicitly refer to a legal requirement for ‘reasonable adjustments’ under the Equality Act 2010 and the NHS and Social Care Act 2008 (Department of Health, 2010; Hatton et al., 2011; Turner, 2014; Turner & Emerson, 2013). Equally, no reference was made to formally assessing the need for reasonable adjustments. Instead, adaptations were described based on prior knowledge of the individual and participants made use of the rhetoric of ‘shoulds and oughts’ drawing on repertoires of fairness as described by Wetherell (1987). Additionally, healthcare professionals talked of the importance of ‘tailored’ care, drawing on available discourses of person-centred care found in diabetes and healthcare services (Care Quality Commission, 2016; Cegala, 2011). Care which did not adapt to the needs of the individual was constructed as inadequate and healthcare professionals or healthcare systems were positioned as blameworthy. This idea was strongest in the accounts of people with learning disabilities, who, in contrast to the position of competent proactive patient described above, sometimes took up positions of incompetence, disability and dependence to make criticisms of appointments which did not fulfil the responsibility to adapt to their needs.

The types of adaptations described as good care by participants in this study match some suggestions made in guidance on reasonable adjustments to diabetes services for this population (Diabetes UK, 2018). Specifically, participants focused on the importance of accessible information and communication. This is in line with research suggesting that people with learning disabilities may experience difficulties communicating with healthcare professionals about their diabetes (Cardol et al., 2012b; Hale et al., 2011; Rey-conde & Lennox, 2007). Participants therefore drew on ideas of fairness, person-centred care and implicit reference to the ideas behind reasonable adjustments to services to construct quality care. The lack of explicit reference to legal requirements and formal assessments relating to reasonable adjustments may begin to explain previous findings that healthcare professionals and people with learning disabilities report little use of reasonable adjustments to improve the quality of health care for people with learning disabilities (Dimensions, 2019; Michael, 2008; Redley et al., 2019).

The idea that quality care should ensure effective and accessible care through adapting appointments was sometimes undermined. Adjusting appointments was sometimes constructed as impractical by healthcare professionals. People with learning disabilities
also sometimes constructed not overcoming difficulties such as lack of time as reasonable. Furthermore, making adjustments for people with learning disabilities was sometimes constructed as flawed since it may be based on incorrect assumptions that all people with learning disabilities are alike. As described further in section 7.4.3, people with learning disabilities were often categorised as either the same or different from other diabetes patients. When considering adaptations to appointments, supporters and healthcare professionals sometimes drew on a third categorisation; that people with learning disabilities are a heterogenous group. Making reasonable adjustments which assume that all people with learning disabilities are alike was therefore constructed as illogical and unfair since this was based on the potentially incorrect assumption of deficit. In comparison, informal ‘in the moment’ assessments of need ‘tailored’ to the individual were presented as preferable.

7.2.2.4 The role of supporters

The finding that supporters were often constructed as having a role in ensuring effective primary care diabetes appointments is commensurate with previous reports that paid and family carers facilitate appointment attendance for people with learning disabilities (Cardol et al., 2012b; Cardol, Rijken, & van Schrojenstein Lantman-de Valk, 2012a; Hale et al., 2011; Trip, Conder, Hale, & Whitehead, 2015). This repertoire was sometimes used to question the quality of the appointment process, for example, healthcare professionals constructed the appointment experience as flawed when supporters did not play their role (e.g. failed to remember appointments). Conversely, the role of supporters was sometimes minimised. Notably, people with learning disabilities positioned supporters in a back-up role and sometimes constructed the involvement of supporters as unnecessary or a hindrance to quality care. On rare occasions, support that was constructed as unnecessary was presented to make a complaint. This conflicts with reports in the existing literature and guidance on the importance of the involvement of paid or family carers in diabetes care. The function of these conflicting constructions may be seen in the different positionings that support them. Descriptions of support as essential present the individual as disabled and dependent. Positionings of dependence are contrary to people with learning disabilities’ constructions of themselves as proactive independent self-managing patients described above. Positionings of complete dependence are also contrary to discourses in diabetes care on patient involvement and self-management and discourses in
social care on enablement and empowerment. Additionally, learning disability is a stigmatised category (Goffman, 1963; Rapley, 2004). Discursively disassociating oneself from the learning disability label and its attendant attributes has been identified in the existing literature (Finlay & Lyons, 2005; Rapley, 2004; Rouse & Finlay, 2016). For people with learning disabilities, minimising the supporter role or constructing it as redundant may therefore be a way of avoiding a stigmatised identity and building an identity as an independent, self-managing diabetes patient.

Although supporters did sometimes position the person they supported as competent and proactive in their diabetes care, they drew predominantly on constructions of people with learning disabilities as partially competent and having supported involvement. This meant that for an appointment to be effective, the support of a more competent person (themselves) was necessary. It may be difficult for paid supporters to position people as entirely dependent and uninvolved even when describing others performing many specific tasks because this goes against discourses of independence. As previously observed, since people with learning disabilities are often positioned as lacking competence and support staff can be positioned as accountable, constructing people they support as entirely autonomous raises a dilemma for support staff. It opens them up to accusations of neglect and failing to manage risk. The insistence of support staff in this study that the person is in need of at least some support may reflect management of these dilemmatic ideas as argued by Buchbinder, 2009; Rouse & Finlay, 2016 and Silverman, 1987b. The need for support was often constructed by supporters drawing on the idea that the individual they support had specific competence but was dependent on support in other tasks. This may make it difficult for people with learning disabilities to argue for increased independence and involvement in their appointments.

Therefore, the role of supporters and their impact on the quality of appointments was variously constructed. How their role was constructed had implications for identity management for the person with learning disabilities and the supporter. The dominant discourses and positionings of competence for people with learning disabilities have implications for the level of involvement each party could have in the appointment process.
7.2.2.5 Responsibility for quality care

According to Taggart et al. (2012) inequalities in diabetes care experienced by this population may centre on the question of responsibility. Social constructionist analyses of accounts of people with diabetes have demonstrated that speakers variously position responsibility as with the patient, healthcare professionals and family members, with implications for diabetes care (Broom & Whittaker, 2004; Ingadottir & Halldorsdottir, 2008; Parry, Peel, Douglas, & Lawton, 2006; Rouse & Finlay, 2016). In this study, members of all stakeholder groups positioned people with learning disabilities, supporters, healthcare professionals and others as having some level of responsibility for ensuring an effective successful experience of primary care diabetes appointments. All stakeholders positioned people with learning disabilities as having a limited level of responsibility. This shows similarities to previous findings that this population is positioned as having supported responsibility and that overall accountability is positioned with more competent others (Rouse & Finlay, 2016). People with learning disabilities and supporters more regularly positioned responsibility with healthcare professional and services and positioned professionals as accountable for inadequate care. Healthcare professionals also sometimes positioned themselves and primary care services as responsible for providing quality care. However, this often consisted of giving examples of care adapted to the needs of the individual and they did not describe examples of poor care. Instead, this group of participants sometimes positioned responsibility away from themselves/primary care practices, constructing quality care as constrained by factors outside their control. This included positioning behaviour or characteristics of people with learning disabilities as barriers to quality care for this population (see section 7.4.1 for further discussion of quality as constrained). The ability of healthcare professionals to discursively manage responsibility for quality diabetes care for this population may reflect previous findings that healthcare professionals do not view themselves as responsible for the healthcare of people with learning disabilities (Webb & Stanton, 2009a). All stakeholders constructed responsibility as with others, which allows speakers to avoid taking responsibility for quality of care or improving services by constructing barriers as beyond the control or responsibility of the speaker.
7.2.3 Repertoires of knowledge

Within all stakeholder groups, the idea was present that knowledge entitles people to make decisions relating to diabetes care and that successful decisions (defined in terms of improvements to lifestyle and outcomes such as weight loss) are made by those who know best. There were differences in the ways that speakers from different stakeholder groups constructed knowledge, with supporters and healthcare professionals making greater use of this repertoire than people with learning disabilities. Since possessing knowledge was presented to support entitlement to decision-making and control over diabetes care, dominant ideas about who knows best have implications for the autonomy of people with learning disabilities regarding the management of their condition.

People with learning disabilities and supporters sometimes constructed themselves as knowledgeable about their diabetes care and the appointment process by describing knowledge gained through experience. Experiential knowledge was sometimes presented and contrasted with the less valuable medical knowledge of healthcare professionals to construct care as inadequate. This is consistent with reports in the existing literature that people with learning disabilities position themselves as having an experiential understanding of their condition (Rouse & Finlay, 2016) and describe themselves as having better knowledge than professionals in consultations (Maine, 2017). Constructions of people with learning disabilities as competent and knowledgeable have also previously been found in accounts of people with learning disabilities to support making complaints (Jingree & Finlay, 2011). People with learning disabilities also drew on the alternative positioning of themselves as lacking knowledge and so reliant on more knowledgeable healthcare professionals and supporters to inform them on medication and aspects of diabetes care.

Both supporters and healthcare professionals constructed the credibility of their own ‘professional’ knowledge by contrasting it to the knowledge held by others. Supporters often positioned themselves as having experiential knowledge of the individual, which was constructed as more successful in improving diabetes care. For supporters, experiential knowledge of the individual was more useful than healthcare professional medical knowledge when it came to agreeing and implementing lifestyle changes such as improved diet and exercise. Supporters did occasionally describe professionals as having experiential knowledge of the person leading to person-centred care, but more commonly constructed
professionals as having medical knowledge but lacking understanding of the individual.

This is consistent with previous research which has argued that a lack of understanding of people with learning disabilities by healthcare professionals may impact on the quality of the experience of appointments (Kelly, 2011; Napthine, 2001; Rey-conde & Lennox, 2007).

All participants constructed healthcare professionals as having superior medical knowledge of diabetes but often constructed experiential knowledge as superior to medical knowledge. On the other hand, healthcare professionals also regularly constructed themselves as having a good knowledge of the individual with learning disabilities or people with learning disabilities generally in addition to their medical knowledge.

The discursive deployment of these constructions of different types of knowledge shows similarities with previous observations that speakers make use of repertoires of knowledge to present themselves as knowing best, thereby strengthening their argument for or against a course of action (Jingree & Finlay, 2008, 2012; Silverman, 1987b). Silverman (1987a) found that in encounters with adolescents with type 1 diabetes and their parents, doctors appealed to their clinical knowledge and medical ‘facts’ whereas parents could ground their claims in their knowledge of their children and their children’s ways. Although parents conceded that professionals have medical expertise, professionals were reluctant to challenge the expertise of parents in assessing how their child ‘seems’. These perceptions could be powerfully deployed, for example, to argue for changes to the treatment regimen (Silverman, 1987b). Parents have also been found to construct their knowledge of their adult child with learning disabilities as personal and practical to present themselves as more knowledgeable than support staff of the person’s best interests (Jingree & Finlay, 2012). In the present study, supporters’ constructions of experiential knowledge built an argument for their professional knowledge to be prioritised over the medical knowledge of healthcare professionals. Healthcare professionals in this study often described patients they had seen regularly, allowing them to draw on repertoires of both experiential and medical knowledge. This combination of experiential and medical knowledge was used to build a strong case for their professional view as correct and the healthcare professional as the best person to make diabetes care decisions. Drawing on these dual repertoires of experiential and medical knowledge may make a persuasive argument that the healthcare professional knows best.
7.3 Differential discourses

This section discusses two discourses that were common in the talk of members of distinct stakeholder groups but rare or absent in others. Specifically, discourses of difficulty were dominant in the talk of people with learning disabilities and ideas of independence as redefined and problematic were strong in the talk of supporters and healthcare professionals. A further repertoire, specific to healthcare professionals (that quality is constrained) is discussed in section 7.4 along with consideration of the specific discursive device that this stakeholder group made use of.

7.3.1 Repertoires of difficulty and the discursive management of complaint

Commensurate with previous findings, the accounts of people with learning disabilities contained descriptions of difficult experiences including being inconvenienced, upset, anxious and experiencing barriers to accessible effective appointments (Cardol et al., 2012b; Care Quality Commission, 2016; Hale et al., 2011; Napthine, 2001; Turner & Emerson, 2013). In this study, discourse analysis identified different ways in which these difficulties were constructed and used as tools for building complaint and performing identity management. Difficulties were sometimes described as reasonable, for example, because practices are busy, which meant that blame was not attributed to healthcare systems or professionals. In this context, difficulties were not considered detrimental to the quality of care. This constructed the speaker as reasonable and uncomplaining with an understanding of the demands of primary care practice, thereby strengthening other complaints within their accounts. The authors of previous research into the social construction of quality care have argued that constructing problems within healthcare as beyond the control of otherwise willing healthcare professionals limits possibilities of improving care quality and restricts the potential roles that stakeholders may play within the care process (Nagington et al., 2013b; Walshe et al., 2013). For example, Walshe et al. (2013) found that despite delayed routine tasks and limited access to care, participants drew on ideas of the ‘busyness’ of nurses who would in theory ‘do anything’ to construct palliative nursing care as quality. The authors argue that the dominance of certain discourses such as ‘busyness’ positioned patients and carers as passive and prevented them re-imagining or asking for more care (because nurses are too busy) and sometimes
made current care unviable (‘we’ll tell someone to do it tomorrow’). Similarly in learning disability research people with learning disabilities have been found to provide justifications for limitations to their independence (Fullana et al., 2019). Although constructions of difficulties as reasonable do not appear to have been dominant in this study, their availability may similarly make it difficult for people with learning disabilities to complain or consider the need for improvements to ‘reasonable’ difficulties with their diabetes appointments. Furthermore, the construction of an uncomplaining, stoical identity as a positive positioning within the role of ‘patient’ may restrict the alternative positioning of complaining patient.

On the other hand, difficulties constructed as avoidable failures were drawn on to build accounts of inadequate care. Unreasonable difficulties were often attributed to the internal characteristics of the professional or other surgery staff. In addition to obstructive/inadequate systems and professionals, people with learning disabilities sometimes drew on positionings of themselves and others with learning disabilities as disabled to describe/complain about difficulties in the appointment process. This contrasts with the more dominant positions of the competent self-managing patient found within the accounts of people with learning disabilities and with evidence that people with learning disabilities do discursive work to avoid the stigmatised identity of learning disability (Rapley, 2004; Rouse & Finlay, 2016). In these examples, speakers took up stigmatised vulnerable identities in order to make complaint. This positioning places responsibility away from the individual for the difficulties they are experiencing and with others (e.g. healthcare providers) to adapt the appointment process to the needs arising from their disability. Participants positioned themselves as unable to complete specific appointment related tasks by foregrounding a disabled identity. This shows similarities to previous observations on the ways in which people with learning disabilities discursively manage identity and draw on repertoires of competence to make a complaint about support staff (Jingree & Finlay, 2011). Here it performed dual functions: identity is managed by warding off a potential positioning of obstructive/uncooperative patient (they are unable to perform/take part in specific activities) and complaint is made against healthcare professionals/systems who do not make necessary adjustments (if the person is dependent, responsibility to ensure accessibility is with others). This again demonstrates that people with learning disabilities are able to flexibly and purposively manage categorical identity (Jingree & Finlay, 2011; Rapley, Kiernan, & Antaki, 1998; Rouse & Finlay, 2016).
As found in previous research (Jingree & Finlay, 2011), speakers sometimes tempered complaint by presenting contrasting accounts of inaccessible unadjusted appointments with instances where appointments had been successfully adjusted in other contexts. This functioned to strengthen complaint by providing evidence that adapting appointments to the individual’s needs was achievable where healthcare professionals and healthcare systems were competent and cooperative. One implication of this rhetorical device was that good practice was often defined in comparison to poor practice so that good care was constructed as willingness to make some adaptation or as an absence of difficulty. This can be seen in Thomas’s descriptions of his appreciation of the willingness of his secondary care practitioner - described as ‘going out of his way’ - to provide easy read information (via the efforts of his secretary once Thomas had requested this) in comparison to the absence of any effort made by his primary care practice. In this way, reasonable adjustments to overcome barriers to effective care were constructed, not as a legal right, but as a favour granted through the efforts of some good healthcare professionals for which the individual was grateful.

It is of interest that people with learning disabilities made more complaints about their experiences of primary care diabetes appointments than the supporters who were interviewed. It may be that people with learning disabilities have more need to attend to identity management to defend their identity as competent self-managing patient. For supporters, describing a good experience may manage identity since they could be considered responsible for ensuring appointments for the person they support go well. However, where both a person with learning disabilities and supporter’s views were available there were sometimes differences in the ways different stakeholders assessed the quality of the same experience as seen in the example of Lynne who stated that the appointment ‘upset me a lot’ and her support worker Lucia who described the same experience as ‘really good’. It may therefore be that in some instances people with learning disabilities and their supporters draw on different ideas about what makes a good appointment.

7.3.2 Independence

Repertoires of independence were drawn on in varying ways to construct different versions of quality care. Supporters drew more regularly and in different ways on ideas around
independence when constructing quality diabetes care for people with learning disabilities than other stakeholder groups.

7.3.2.1 Repertoires of competence and supported autonomy

Research exploring family and staff accounts of diabetes management for adults with learning disabilities (Cardol et al., 2012a; Hillege, Gallagher, & Evans, 2013; Rouse & Finlay, 2016; Whitehead et al., 2016) often includes dilemmatic ideas around dual responsibilities to promote independence and manage risk. Similar conflicting ideas have been found in explorations of talk about autonomy in relation to diabetes care for adolescents (Buchbinder, 2009; Silverman, 1987b) and in staff accounts of increasing autonomy for adults with learning disabilities (Jingree & Finlay, 2008). This study found the same conflicting ideas were commonly drawn on by supporters when formulating quality diabetes care. A dominant discourse in the accounts of supporters was that quality care includes supporters encouraging or allowing autonomy. Within this repertoire, speakers described people with learning disabilities as independently undertaking appointment-related tasks and decision-making. Alternatively, when describing themselves or others taking control of tasks and decision-making, quality care was formulated in terms of safeguarding.

Silverman (1987b) argues that descriptions of promoting autonomy opens doctors to challenges of not taking professional responsibility and family to challenges of uncaring behaviour, whereas not supporting autonomy opens them to accusations of restriction and nagging. These dilemmatic ideas are therefore managed to build/defend a positive, responsible identity. This is done by asserting both principles of responsibility and autonomy simultaneously and by making use of positionings relating to competence (Jingree & Finlay, 2008; Rouse & Finlay, 2016). Similarly, within this project where people with learning disabilities were positioned as competent to complete appointment-related tasks and in their understanding of diabetes care, speakers often drew on the idea that quality care includes promoting or respecting the individual’s autonomy concerning appointment-related tasks and decision-making. On the other hand, when speakers drew on constructions of people with learning disabilities as lacking in competence, they invoked the idea that quality care includes more competent others (supporters and professionals) supporting or taking control of specific tasks and decision-making to ensure successful
appointments and safe and effective diabetes care. Therefore, quality care protects people when they are positioned as vulnerable and lacking in competence, but quality care also supports or allows people to be independent where they are positioned as competent.

A further way of managing these dilemmatic positionings of people with learning disabilities was to reconceptualise the concept of independence when applied to this population. In talk about choice and independence in the lives of adults with learning disabilities, staff and parents have been found to reconstitute the concept of autonomy, constructing bounded frames of empowerment (Jingree & Finlay, 2008; Rouse & Finlay, 2016). Jingree and Finlay (2008) write that drawing on the idea that empowerment is bounded allows staff to position themselves as facilitators of choice whilst maintaining a standard of good safe care. Similar constructions of autonomy as offered or allowed within safe boundaries can be seen throughout the accounts of supporters in this study and to a lesser extent in the talk of healthcare professionals and people with learning disabilities. It is striking that even when quality care was defined according to the promotion of independence, autonomy was often reframed as autonomy within safe boundaries attending to the responsibilities of support staff. The notion of bounded empowerment is strongest in the talk of supporters in this study but can also be seen in some accounts by people with learning disabilities. For example, William describes himself as dependent on the decisions of staff to support his independence and reports them positioning him as lacking the competence to successfully make his own appointments and so withholding power.

The presence of dilemmatic ideas on promoting autonomy and safeguarding and the idea of ‘bounded empowerment’ is familiar in the existing literature (Jingree, 2009; Jingree & Finlay, 2008; Rouse & Finlay, 2016). The present study suggests that although less common, similar conflicting repertoires of independence are available to healthcare professionals when considering quality diabetes care for this population. Notions of supported/bounded independence and decision-making may be at odds with the kind of autonomy promoted in diabetes quality care guidance and independence as constituted by people with learning disabilities such as William. People with learning disabilities may be dependent on the positionings afforded them by more powerful support workers and healthcare professionals who are able to construct varying levels of autonomy as consistent with quality care.
Previous research within learning disability services has investigated how support staff manage the competing discourses on the need to promote autonomy and duty to ensure the safety and wellbeing of the people they support. Speakers often prioritised repertoires of empowerment and autonomy when the individual they support was positioned as competent but prioritised repertoires of risk management and duty of care when positioning the individual as incompetent and vulnerable (Jingree, 2009; Jingree & Finlay, 2008). The NHS RightCare Pathway for people with learning disabilities and diabetes describes the need to balance these considerations, stating that “When planning person centred care it is essential to strike the balance between protecting an individual’s health and their choices. To achieve this, the individual should be given adequate and accessible information to increase opportunity to make informed decisions” (Kachika, 2017: P 19). The focus here is on ensuring accessible information to enable the individual to make informed decisions. The Diabetes UK factsheet on improving diabetes care for people with learning disabilities states that ‘People with a learning disability must be included in decisions about their healthcare and give consent unless it is shown that they do not have mental capacity’ (Diabetes UK, 2019b: P 2). Jingree and Finlay (2008) argue that contrary to the Mental Capacity Act, autonomy in decision-making is often withheld from people with learning disabilities by presenting this population as lacking competence in decision-making skills (cognition, discretion, social competence). Similarly, in this study professionals and supporters sometimes described intervening or taking control in the person’s ‘best interest’ due to lack of competence. For example, taking the decision to control weight/glucose levels through medication because the person is not competent to do so themselves and risks serious complications. Conversely, some accounts drew on ideas of specific competence and the concept of mental capacity, enabling supporters and professionals to build a case for respecting autonomy in the day to day management of diabetes. Risk of poor management and long-term complications were flexibly presented as an argument for taking control or upholding rights to autonomous decision-making depending on whether the person was constructed as having mental capacity. This is in line with my own previous findings that support staff can defend against potential accusations of failure in duty of care during accounts of autonomous diabetes management by drawing on positionings of the person with learning disabilities as possessing mental capacity (Rouse & Finlay, 2016). In the present study, supporters and healthcare professionals sometimes drew implicitly
and explicitly on the Mental Capacity Act to position the person as entitled to choice and themselves as having limited entitlement to intervene, even if they considered the choice to be unwise. Within this repertoire competence was informally determined by the individual’s knowledge of diabetes care or healthy eating (the person knows that sweets are bad for them). However, capacity determined by competence in knowledge is constructed as problematic due to specific incompetence such as inability to link present behaviours with future consequences (poor diet leads to liver damage). This repertoire acknowledges discourses on the importance of autonomy for this population and the legal principle of assuming competence. Capacity is equated with an understanding of the abstract facts (e.g. sweets are bad for you) not the ability to put this knowledge into practice.

When making reference to mental capacity, autonomy was not described as desirable or empowering, but an uncomfortable concept which limited the speaker’s ability to improve diabetes care and prevent risky health related behaviour. Drawing on the repertoire that independence is problematic performed identity management for speakers who could be considered as having a duty of care for people with learning disabilities. Drawing on ideas around the Mental Capacity Act acknowledged the speaker’s awareness that the behaviours were risky, but presented non-intervention in dangerous health related behaviour as a moral and legal obligation. It is notable that at times when supporters and professionals described undermining autonomy, they did not make reference to the Mental Capacity Act. The appeal to legal rights makes a powerful argument for not intervening whilst managing the speaker’s identity; whatever the view of the speaker on the wisdom of the individual’s decision, legally they are powerless to intervene. As previously identified in discourse about people with learning disabilities it drew on what Wetherell (1987) described as the moral language of ‘shoulds, oughts, fairness and duty’ (Jingree and Finlay, 2008; Ramcharan & Borland, 1997 in Dowson, 1997) to present a positive liberal identity (i.e. they understand that people with learning disabilities have the same rights as others). This has implications for the extent to which autonomy is promoted and interventions that are made to prevent risky diabetes care. The prioritisation of the right to choice by support staff over a healthy life is a matter of debate (Hatton, 2016). This study demonstrates that drawing on ideas around the Mental Capacity Act is one way to manage dilemmatic ideas on the topic and that these resources can also be drawn on by healthcare professionals.
7.4 Discursive devices

7.4.1 Quality as constrained - Practicalities talk and the practice/principal rhetoric

Rather than difficulties caused by flaws within their own practice, healthcare professionals made use of practicalities discourses to construct constraints on quality care as beyond their control. The appeals to practical obstacles is a rhetorical device which has been previously described in the discourse analysis literature (Jingree & Finlay, 2008; Wetherell et al., 1987; Wilcox et al., 2006) including the social construction of quality care (Nagington et al., 2013a; Walshe et al., 2013). For example, Jingree and Finlay (2008) found that support workers presented practical considerations as an unalterable reality to be worked around and that this functioned to justify not facilitating choice for people with learning disabilities in some situations. The present study found that healthcare professionals similarly made use of practicalities talk to account for care that did not have successful outcomes (e.g. improved diet) or did not achieve the recommended care processes (e.g. retinal screening, foot checks).

As described in previous explorations of care staff talk about people with learning disabilities (Jingree & Finlay, 2008; Wilcox et al., 2006), healthcare professionals made reference to both internal and environmental obstacles described as ‘individual pathology discourse’ and ‘context discourse’ (Wilcox et al., 2006). Healthcare professionals in this study described quality care as hindered by internal obstacles (the person’s learning disability/uncooperative ‘naughty’ nature) and environmental obstacles (rules, lack of funding or inadequate support at home). In common with previous findings (Jingree & Finlay, 2008; Wilcox et al., 2006), drawing on an individual pathology discourse constructed the obstacle as fixed. Environmental obstacles can be constructed as flexible, as seen when speakers constructed professionals as responsible to adapt appointments to the needs of the individual. However, within practicalities discourse, environmental obstacles were constructed as inflexible in specific contexts (when dealing with decisions made by others, diabetes care outside of the medical encounter). Presenting obstacles as beyond the power of the speaker to change, functioned to distance the practitioner from responsibility for appointment processes and care outcomes that did not match quality care guidelines or ideas of fairness and equality drawn on elsewhere in accounts. This was often combined
with expressions of frustration with practical obstacles and descriptions of unsuccessful efforts, which presented the speaker as doing their best but ultimately powerless in the face of unalterable constraints.

Healthcare professionals performed further identity management by drawing simultaneously on practicalities discourse and talk of a theoretical ideal. According to Wetherell et al. (1987) drawing on the principle or theoretical ideal contrasts the speaker with those who do not believe in the ideal, establishing a positive identity as someone with good moral intentions. Practical considerations are presented as unalterable facts independent of the speaker’s beliefs or wishes. Wetherell et al. (1987) argue that when the theory/practice distinction is seen in talk, references to practical considerations neutralises the ideal but presenting the ideal allows the speaker to build a positive identity. When presented in talk on equality Wetherell et al. (1987) describe this as ‘unequal egalitarianism’. Healthcare professionals in my study sometimes presented the principle of equal care in line with quality diabetes care guidelines, taking up the identity of a moral professional and believer in quality and equitable care. Where this principle was presented alongside practical considerations such as the uncooperative, emotionally incompetent nature of people with learning disabilities, the ideal of quality equitable care was negated by practical considerations outside of the speaker’s control (the person may not cooperate and/or become distressed). The theory/practice distinction functions to maintain the status quo by restating belief in the ideal (people with learning disabilities should receive equal care) but this ideal is then made irrelevant by ‘practical talk’ (but people with learning disabilities won’t/can’t cooperate) (Wetherell et al., 1987). Such talk makes a case against changing current care provision and in fact makes quality improvement by healthcare professionals impossible. Responsibility for the practical obstacles is attributed to people or systems outside of the practitioner’s control. Use of the practice principle device allowed healthcare professionals to draw on discourses about the importance of quality care standards and equitable care whilst giving accounts of care that did not meet these standards and present a positive moral identity. Although they believe in good and equitable care for people with learning disabilities, practicalities beyond their control sometimes make this impossible.
7.4.2 Autonomy and the moral principle

A further form of the practice/principle device found was the criticism/concession disclaimer (Wetherell & Potter 1992) whereby the moral principle is stated (liberal principle of choice) and then undermined by an incompatible moral principle (people with learning disabilities are vulnerable and need protecting). This is similar to findings in the present study that supporters and professionals drew on different and competing principles of the need to promote independence and choice (in which people with learning disabilities are positioned as like anyone else with diabetes) and the need to support and protect people with learning disabilities in their diabetes care (in which they are positioned as dependent and vulnerable) (Jingree, 2009; Jingree & Finlay, 2008). As found by Jingree (2009), this device was sometimes used to prioritise guardianship discourses over the need to promote independence and choice. However, an alternative use of this discursive device can be seen in discussions of capacity. Here, the moral imperative to uphold the legal rights of people with learning disabilities and capacity to make an unwise choice/have independence and choice in their diabetes management is prioritised over the moral principle of guardianship and protection. People will make choices that are bad for them and staff/professionals could have a moral duty to intervene but this would conflict with the other moral principle presented – to uphold their human rights to choice and control over their own lives. Jingree (2009) argues that the practice/principle device is a persuasive strategy for invalidating the discourse of increasing autonomy for people with learning disabilities, whilst presenting a positive liberal identity. Empowerment is bounded by what is considered practical, so that practice/principle talk on this topic is disempowering. Interestingly, in the present study practicalities talk was sometimes used to undermine the control that people with learning disabilities have over their diabetes care (they lack competence to deal with hypoglycaemia, book appointments) and at other times practicalities talk justified the prioritisation of autonomy (limiting autonomy would be contrary to the individual’s legal rights). However, it could be argued that in the situations described by supporters and practitioners, drawing on the idea of capacity does not function to increase empowerment but instead maintains and justifies the status quo. For example, support worker Karen and dietician Alison describe risky unhealthy eating behaviours by the person with learning disabilities in which staff and professionals do not intervene. Citing the moral principle of upholding rights as prioritised against guardianship in this instance supports maintaining choice and again makes change unnecessary and
perhaps against the moral principle of human rights. Practicalities discourses and obstacles were used by support staff to excuse not giving choice in some situations and allowed staff to also position themselves as facilitators of choice whilst justifying lack of success in overcoming these obstacles.

7.4.3 Categorisation of people with learning disabilities as the same or different to the non-disabled population

Discursive psychologists have demonstrated that categorisation is a pervasive and powerful resource for making sense of our social world (Edwards & Potter, 1992; Potter, 1996; Potter & Wetherell, 1987). Within talk, people are often categorised, with speakers drawing on shared knowledge of activities and traits of category members. Categories can be selected, flexibly constructed and taken up or assigned to others in interaction to achieve goals such as blaming and mitigation (Potter & Wetherell, 1987). Categorisation is an important discursive resource in talk about and by adults with learning disabilities (Rapley, 2004). The category ‘learning disability’ can be flexibly constructed to attribute or defend against a stigmatised identity by taking up or resisting characteristics usually associated with membership of the category learning disability (Finlay & Lyons, 2005; Rapley, 2004; Rouse & Finlay, 2016). People with learning disabilities can also be constructed by others as the same or different to people without disabilities (Jingree & Finlay, 2008) supporting different ideas on their abilities, rights and entitlements. In addition to the categorisations discussed in section 7.2, speakers drew on categorisations of similarity and difference when talking about people with learning disabilities.

Throughout the accounts in this study, the category of ‘learning disability’ was variously constructed as including attributes of difference or similarity to other people with diabetes and/or the general population more broadly. Categorisations of learning disability which focused on difference were put forward to justify or argue for differences in diabetes care and contributed to constructions of quality care as having different outcomes and goals for this population. Categorisations of people with learning disabilities as the same as other people with diabetes were presented to argue that quality care is equal care which should achieve the same goals for everyone, presenting assumptions of difference as inadequate and morally incorrect.
Rapley (2004) writes that membership of the learning disability category performs moral work and can disqualify a person from entitlement to membership of the category ‘ethical, confessing, human subject’. People with learning disabilities are defined by incompetence and their membership of the category of competent human is subtly managed and often withheld by support staff (Rapley, 2004). Supporters in this study did categorise people with learning disabilities as different to others, making a comparison between ‘us’ (cognitively competent and straightforward for professionals to talk to) and ‘them’ (lacking ability to understand and communicate). The category ‘person with learning disability’ includes the attribute of being ‘human’ or a ‘person’ with the attendant rights to be viewed as a ‘patient’ who is the focus of the appointment as well as rights to be informed, treated with respect and to have independence and choice in relation to their diabetes care. The rights associated with being a human patient were not dependent on competence but remained despite positionings of the person with learning disabilities as different. The category of learning disability as incompetent or different was reformulated to different but ‘human’ with the same rights and expectations of equal treatment from their diabetes healthcare professionals as anyone else. This places a moral accountability with healthcare professionals to acknowledge the person as human with the same rights as other members of the category ‘human’, a category which is sometimes at risk of being obscured by membership of the category ‘learning disability’. The need to assert that the category ‘learning disability’ includes being human perhaps attends to traditional and dominant discourses of deficit and the idea of people with learning disabilities as lesser. It also reflects the emphasis in policy documents that people with learning disabilities have the same human rights and legal entitlements as anyone else (Department of Health, 2001b; NHS Improvement, 2018). This categorisation was sometimes used to make criticism of professionals who did not provide equitable treatment. It also built positive liberal identities for professionals and supporters since foregrounding this categorisation distanced them from the idea that they themselves do not consider people with learning disabilities as human.

Constructions of people with learning disabilities as different to other people with diabetes may relate to finding that healthcare professionals sometimes make clinical judgements to aim for different treatment targets for patients with learning disabilities than patients in the non-disabled population (Brown et al., 2017). For example, Linda, a Nurse Practitioner, described use of appetite suppressants for this population due to their difficulty managing diet and constructed people with learning disabilities as lacking the competence to manage
hypoglycaemia which impacts on treatment decisions. Categorisations of people with learning disabilities as different, lacking competence and vulnerable demonstrates one way in which the idea of different care is discursively constructed as safe and morally correct.

7.5 Conclusion

This research adds to our understanding of how quality diabetes care is constructed in accounts of primary care diabetes appointments for adults with mild-to-moderate learning disabilities. Similarities and differences were found in the repertoires and subject positions commonly drawn on by different stakeholders. Repertoires common to all stakeholder groups were that quality is dependent on the achievement of the appointment’s purpose and on key stakeholders fulfilling their roles and responsibilities. Notable differences were that people with learning disabilities drew on repertoires of reasonable and unreasonable difficulties, supporters and healthcare professionals constructed independence as problematic and quality was constructed as constrained by healthcare professionals. Responsibility for quality care was variously and purposively positioned with different stakeholders. The project also contributes to understanding of the use of some key discursive devices in the construction of quality care for this population and the management of identity by members of all stakeholder groups. Overall, quality care in terms of primary care diabetes appointments for this population was flexibly constructed. The available and dominant repertoires and positions have implications for whether quality is considered open to or in need of improvement and how quality care is assessed by key stakeholders. Some available repertoires and discursive devices can be used to justify and maintain power relations and inequalities within diabetes care for this population.

In the final chapter I will revisit my research questions, summarise the key findings, explore the strengths and limitations of the study and describe implications for future research, policy and practice.
Chapter 8  Conclusion

The existing literature tells us little about how the meaning of quality diabetes care is constituted by key stakeholders in relation to diabetes care for people with learning disabilities. My thesis aimed to enhance understanding of this topic by exploring the social construction of quality care and responsibility for quality care within accounts of the experiences of diabetes primary care appointments by adults with mild-to-moderate learning disabilities, supporters and healthcare professionals. Specifically, this thesis aimed to examine the discursive resources or interpretative repertoires drawn on by stakeholders, how they positioned themselves and others in relation to quality care and to identify any similarities or differences in the constructions of quality diabetes primary care by different stakeholders. This chapter will begin by summarising my findings in terms of the three research questions described in chapter 2. I will then consider the methodological strengths and limitations of my PhD research, discuss implications of my findings for policy and practice and make suggestions for future research arising from this thesis.

8.1  Research Questions

8.1.2  The social construction of quality care

As outlined in chapter 2, my first research question asked how adults with mild-to-moderate learning disabilities and diabetes, those who support their diabetes management and healthcare professionals discursively constructed quality diabetes primary care appointments. Through application of the analytic tools of interpretative repertoires, subject positions and ideological dilemmas, quality care was found to be variously and purposively constructed. Different versions of quality care were flexibly presented to perform identity management for the speaker, to attribute responsibility for the quality of care and to construct entitlement to autonomy or intervention in appointment related tasks and diabetes care more broadly.
A key idea in the accounts of all stakeholders was that the quality of diabetes care appointments is dependent on the achievement of appointment goals. Appointments were good quality if they successfully achieved the aims of diabetes primary care appointments, whereas instances of failure to achieve appointment purposes were presented as evidence of inadequate or poor quality care. Within this repertoire, speakers were able to draw on different ideas of the purpose of these appointments informed by categorisations of people with learning disabilities as the same or different from other people with diabetes. Appointment goals were sometimes in line with recognised quality standards for diabetes care, such as the provision of information and monitoring of diabetes through care processes. However, the appointment goals presented were sometimes at odds with recommendations and guidance on diabetes care where good care was constructed as having adjusted goals for this population. Specifically, care processes recommended in quality standards and guidelines for diabetes care were sometimes absent from the appointment aims because they were attributed to other sources such as support staff or were presented as incompatible with the less health structured focus of appointments for this population. This may provide some explanation of previous findings that diabetes care processes are not always completed or are completed less often for this population than for people with diabetes who do not have learning disabilities. It also demonstrates ways in which the conflict between recognised care standards and practice which does meet these standards may be discursively managed by key stakeholders to present a positive professional identity. Quality care was therefore sometimes equated with achievement of recognised care standards but flexible construction of quality in relation to this population could be used to construct care which failed to achieve these standards as quality care.

Another prevalent way of constructing quality diabetes care appointments drew on the idea that quality care requires stakeholders to fulfil their roles and responsibilities. Quality diabetes care was associated with people with learning disabilities playing an active role as diabetes ‘patients’ but what constituted a proactive ‘diabetes patient’ for this population was flexibly constructed. It may consist of active involvement in communication with healthcare professionals and other appointment related tasks or giving permission for diabetes care practitioners and supporters to talk about your diabetes care.

Supporters constructed themselves as necessary to some degree in the experience of quality care for the individual. On the other hand, people with learning disabilities drew on varying positionings of the value of supporters in terms of quality care. The involvement of
supporters was sometimes constructed as essential to the effectiveness of appointments, at other times their involvement was presented as unessential (with no impact on quality) or as a hindrance and so contributing to a poorer quality experience (e.g. through obstructing independence). This may indicate some tension between the ways in which the role of the supporter is constructed by different stakeholders.

Healthcare professionals/care systems fulfilling their responsibility to adapt appointments to the needs of the individual constituted quality care, whereas failure to do so was constructed as inadequate care. Strikingly, this responsibility was constructed by drawing on repertoires of fairness (what professionals ‘should’ do), person-centred care and informal knowledge of the individual rather than references to formal assessments or legal requirements to make reasonable adjustments. This lack of explicit reference to legal requirements and formal assessments may begin to explain previous findings that healthcare professionals report making little use of reasonable adjustments to improve the quality of health care for this population (Redley et al., 2019).

Knowledge was an important concept drawn on to construct quality diabetes care appointments. Speakers presented effective diabetes care appointments as informed by two types of knowledge: medical knowledge (of diabetes and medication) and experiential knowledge (of one’s own body/condition, the individual with diabetes and the context of disease management). Participants often constructed the knowledge they held as more effective than the knowledge held by other stakeholders, thus positioning themselves as knowing best how to achieve a successful appointment experience and effective diabetes care. Supporters and people with learning disabilities constructed healthcare professionals as having superior medical knowledge but often constructed their own experiential knowledge as of greater relevance to effective diabetes care than medical knowledge. On the other hand, in addition to their medical knowledge, healthcare professionals also regularly constructed themselves as having a good knowledge of the individual with learning disabilities or people with learning disabilities generally. The ability to draw on both repertoires of medical and experiential knowledge allowed healthcare professionals to make a persuasive argument for their entitlement to lead decisions relating to diabetes management since it positioned them as comprehensively informed/knowing best and thus acting on their knowledge as more likely to result in success.
8.1.3 Similarities and differences in the social construction of quality care appointments

The second research question aimed to shed light on any similarities and differences in the ways in which different stakeholders discursively constructed quality diabetes care appointments for people with mild-to-moderate learning disabilities. As described above, speakers from different stakeholder groups drew on some common ideas about what constitutes quality diabetes care appointments. These included that appointments should fulfil their intended purpose, stakeholders should fulfil their roles and responsibilities and that effective decisions are made by knowledgeable people. Within these commonalities, some differences can be seen in the predominant ideas on quality care. In particular, people with learning disabilities drew more than other stakeholders on the idea that quality care was dependent on their proactive role and sometimes resisted the positioning of dependence on supporters to make their appointments effective. Conversely, supporters and healthcare professionals drew more on the idea that people with learning disabilities lacked competence and that quality care depends on support from more competent others, emphasising the role of supporters and professionals in ensuring effective diabetes care appointments. As described above, people with learning disabilities and supporters positioned themselves as having experiential knowledge, whereas healthcare professionals were able to reference a combination of experiential and medical know how.

In addition to the nuances within the common repertoires described above, a number of differences were found in the repertoires that members of different stakeholders drew on to construct quality diabetes care appointments. People with learning disabilities talked of quality in terms of reasonable and unreasonable difficulties with their appointments. Difficulties were constructed as reasonable and justifiable and so did not impact of the quality of care. Alternatively, difficulties were presented as avoidable failures and used to build complaints against healthcare systems and practitioners. This contributes to our knowledge of how this population makes complaint. Drawing on this repertoire functioned to make complaint but also demonstrates restrictions to the possibility of questioning quality diabetes care where difficulties can be constructed as reasonable.

Supporters drew on different and more prevalent ideas about the relationship between independence and quality diabetes care for people with learning disabilities.
Independence was presented either as a necessary component of quality care or as a problematic and risky concept when applied to the diabetes care of people with learning disabilities. Whether or not autonomy was constructed as important depended on how the person with learning disabilities was positioned. Where the person was positioned as competent, supporters/professionals were positioned as responsible to promote their autonomy. Where the person was positioned as lacking specific competence, supporters/professionals were often positioned as having overall accountability and entitled to take control to manage risk. Supporters and professionals also drew on the idea that independence and empowerment for this population is supported or ‘bounded’ by more competent people (supporters and practitioners) who have overall accountability and so contain risk. One way in which supporters managed the conflicting repertoires around independence and choice in diabetes appointments was by appealing to ideas of competence, capacity and understanding. If people lack the understanding to make a safe choice, or for the appointment to be successful, staff are entitled if not responsible to intervene through support, guidance and advice. If people are positioned as having capacity to understand the impact of a poor choice and the competence to be successfully independent, staff are not entitled to intervene. In this way, staff distanced themselves from repertoires of force and control, but instead constructed independence as supported and choice as guided. This reflects previous findings that staff and family construct independence and choice in a different way for the people they support, as permitted within safe boundaries (Jingree & Finlay, 2008; Rouse & Finlay, 2016). This has previously been described as ‘bounded empowerment’ and fits with the idea that empowerment as usually understood is an illusion within services for people with learning disabilities – loaned but not given by support staff (Dowson, 1997).

Of particular interest within the repertoire of independence is the way that some supporters and professionals (but not people with learning disabilities) drew on ideas around the legal framework of the Mental Capacity Act. These ideas were applied in an inconsistent and complex way within the context of diabetes care for people with learning disabilities, with participants describing informal assessments of Mental Capacity in specific situations. Discursively, speakers did not make consistent reference to the Mental Capacity Act to explain/justify autonomy in the context of diabetes care for this population. Instead, principles of the Mental Capacity Act (2005) were purposively drawn on to justify non-intervention in what could be considered risky diabetes management but were absent when speakers described intervening or taking control of the person’s diabetes care. The
Mental Capacity Act and its principles were therefore a discursive resource that speakers could appeal to in order to manage their professional identity when describing non-intervention in what could be considered unwise/risky diabetes management by the individual. This allowed speakers to acknowledge that they recognised risky behaviour but were morally and legally unentitled to intervene.

Distinct from other stakeholder groups, healthcare professionals made use of practicalities rhetoric to construct quality care as constrained by obstacles beyond their control. This enabled speakers to describe care with poor outcomes or appointments which did not match diabetes care quality standards whilst maintaining/defending a positive professional identity. In this case, quality care was equated with trying and effort but being realistic about practical constraints. This may further explain how professionals discursively manage the tension between quality standards and practice which falls short of these.

8.1.4 Responsibility for quality care

The final research question asked how key stakeholders discursively constructed responsibility for the provision of quality diabetes care for adults with learning disabilities. Different stakeholders were constructed as having different responsibilities in relation to ensuring the effectiveness of diabetes primary care appointments for this population. Broadly, healthcare professionals were positioned as responsible for ensuring appointments were adapted to the needs of the individual, people with learning disabilities were positioned as responsible to take a proactive role such as communicating with their healthcare professionals, and supporters were positioned in a supporting role, ensuring that the individual is able to play a proactive part in their appointments. Whilst all stakeholders constructed responsibility for quality care as shared to varying extents, all stakeholders also positioned people with learning disabilities as having a limited level of supported responsibility and positioned overall accountability with more competent others. This dominant positioning may inhibit the ability of people with learning disabilities to be positioned by others as independent, competent and responsible for their own diabetes care appointments.

Responsibility for care constructed as inadequate was often discursively managed to position accountability away from the speaker, for example, through stories of the poor
practice of other stakeholders or constructing care as constrained. This discursive management of responsibility for quality diabetes care allowed speakers to avoid taking responsibility for quality of care or improving services by constructing barriers to quality as beyond the control of the speaker.

8.2 Implications and recommendations

The findings of this research have implications for evaluating and improving diabetes primary care appointments for adults with learning disabilities and may be applicable to other areas of healthcare for this population.

Findings on the ways in which stakeholders construct purpose fulfilment in relation to quality care may be of interest to diabetes care services and in the design and assessment of quality care standards. Specifically, although achievement of some goals outlined in care guidance was sometimes equated with quality care (informing and assessing) it was possible for speakers to construct appointments as good quality which did not include all recommended diabetes care processes. This may mean that people with learning disabilities are unlikely to raise issues considered beyond the remit of the appointment, such as emotional distress due to diabetes, with their healthcare professionals or to make complaint if care processes/topics constructed beyond the purpose of the appointment are not covered. Promotion of existing adapted guidance aimed at people with learning disabilities on diabetes care and extension of these documents to include easy read versions of diabetes care quality standards by Diabetes UK and NICE may be valuable in improving awareness of what should be expected from diabetes care appointments. It is notable that the limited existing easy read guidance on diabetes aimed at this population often excludes information on the same topics that participants with learning disabilities situated outside of the remit of their diabetes appointments, for example: emotional support, access to structured education programmes, and topics related to pregnancy and sexual health. These topics could be usefully added to existing easy read guides to diabetes care. Awareness of adapted diabetes structured education programmes for this population could also be raised for all stakeholder groups.

Furthermore, it was possible for healthcare professionals to construct quality care as appointments that did not include all recommended care processes, or formally consider
reasonable adjustments. Additionally, healthcare professionals usually ascribed poor quality care to barriers beyond the control of professionals and primary care services. All of this may make it difficult for healthcare professionals to consider improving diabetes care provision for people with learning disabilities since they support a conclusion that improvement is unnecessary or out of the hands of healthcare professionals. Of particular interest is that in constructing the purpose of appointments and roles and responsibilities, participants from all stakeholder groups did not refer to legal rights to ‘reasonable adjustments’. Drawing instead on ideas of informal judgements of person-centred and ‘realistic’ care may make formal consideration of reasonable adjustments appear unnecessary (e.g. retinal screening cannot be achieved for this person so it should not be tried). This contrasts to the diabetes care guidance for this population that reasonable adjustments should be made to ensure care processes are accessible (Kachika, 2017). It may therefore be of value to promote existing guidance on reasonable adjustments to diabetes care for people with learning disabilities to diabetes healthcare professionals. This could help clarify that rather than excluding people with learning disabilities from the recommended processes, any difference in goals for this population should focus on adjusting services to make care processes accessible.

Since different stakeholders sometimes drew on conflicting ideas around what constitutes quality diabetes care, sharing of different perspectives may also be of value. For example, professionals may benefit from training by people with learning disabilities to gain insight into their likes, dislikes and views on ways in which appointments can be made more accessible and effective. Creation of quality standards and the design and commissioning of diabetes care services with input from all stakeholders may also be of value.

Current advice on reasonable adjustments to diabetes care for people with learning disabilities recommends working with paid or family carers. It may be useful for healthcare professionals to be aware that people with learning disabilities do not always consider the presence of a carer to constitute a good appointment, indeed it may be detrimental to the quality of their experience. Along with the resistance of dependent identities by people with learning disabilities, this emphasises the need for healthcare services to engage the individual with learning disabilities in their diabetes care and the importance of avoiding assumptions about the competence of the individual and the roles that the individual and anyone supporting them may play in their diabetes care.
There are possible implications of the tendency of support workers and healthcare professionals to construct the Mental Capacity Act as problematic and a constraint to successful diabetes care since it prevents supporters and professionals intervening in healthcare behaviours because they consider them to be unwise (see sections 5.5.2 and 6.5.3). Capacity was dependent on one type of competence (general understanding) regardless of incompetence in the specific area of understanding long-term consequences, an understanding which is particularly important in relation to diabetes care. Additionally, assumptions of capacity were based on informal knowledge of the individual rather than formal assessments. Ideas around mental capacity were flexibly drawn on and sometimes removed the entitlement of others to intervene but at other times supporters and professionals described taking control of diabetes care and decision-making due to lack of competence. Healthcare professionals and support workers may need greater clarity on the Mental Capacity Act (2005) and how it relates to people with learning disabilities and their day to day diabetes care, particularly in relation to entitlement to intervene in the case of diet that is damaging.

People with learning disabilities sometimes positioned supporters rather than healthcare professionals as sources of information on day to day diabetes care such as diet. Supporters in this and other research have reported a lack of formal training in diabetes care (their knowledge is experiential) (Cardol et al., 2012a). Making people with learning disabilities and their supporters aware of topics that they can raise with healthcare professionals and ensuring supporters are equipped to provide such information (e.g. through diabetes courses) may be of value.

Some commonly drawn on discourses relating to quality care by supporters and healthcare professionals have the potential to restrict the opportunity for people with learning disabilities to be informed and involved in diabetes care related decisions and to receive the recommended care processes for people with diabetes. Speakers are often unaware of the contradictory themes in their talk, and the possible impact of the resources used to discursively manage these dilemmas (Billig et al., 1988). Making people familiar with how others are positioned during talk can bring about change (Burr, 2015). Training which highlights potentially restrictive discourses relating to quality diabetes appointments may help to challenge talk which reproduces inequalities in diabetes care.
In summary, the findings of this thesis suggest that diabetes education aimed at people with learning disabilities and support staff may benefit from highlighting the care that people with diabetes should expect from their appointments including the topics that can be discussed with healthcare professionals. Additionally, training for healthcare professionals could point out that people with learning disabilities and their supporters may be unaware of what to expect from appointments and so may not raise topics without prompting. Education programmes aimed at healthcare professionals could also usefully cover reasonable adjustments and the legal framework around mental capacity in terms of diabetes care for this population. Equally, when considering policy and practice, healthcare policy on diabetes care provision may benefit from clarification of these topics and from designing care provision in which anticipatory reasonable adjustments are routine practice. Policy makers might also consider elucidating the goals of quality diabetes care including whether/how they may differ from the goals for people without learning disabilities as well as clarifying the roles and responsibilities of stakeholders. Diabetes care practice could aim to prompt coverage of all topics outlined in diabetes quality care guidance in an accessible way. For example, this might include encouragement of pre-appointment preparations using accessible forms for people with learning disabilities and supporters. Responses during the interview process and feedback from presentations on this thesis suggested limited awareness of the existing guidance on diabetes care for people with learning disabilities. Wider promotion of such tools as the NHS Right Care Pathway for people with diabetes and learning disabilities and Diabetes UK’s guidance to diabetes care for people with learning disabilities (Diabetes UK, 2015a; Kachika, 2017) may therefore be of value.

8.3 Strengths and Limitations of the research

The methodology of this research had several strengths and limitations. Making use of a critical discursive psychological approach to data analysis revealed the discursive ideas and resources available to speakers when considering quality diabetes care and the function of their flexible use for participants, for example, that dominant positionings on incompetence/dependence of people with learning disabilities are available to supporters and healthcare professionals. This approach also helped further understanding of how tensions between conflicting ideas and inequalities identified in literature taking a positivist approach can be discursively produced and managed. For example, the tension between
diabetes care standards, which equate quality with the achievement of care processes, and audits and survey results that indicate people with learning disabilities do not always receive recommended care processes was found to be discursively managed in a way likely to maintain this difference or inequality. This approach further revealed the subtle and informal application of ideas around legal requirements of reasonable adjustments and the Mental Capacity Act despite participants often directly reporting that ‘reasonable adjustments’ and formal assessments of mental capacity were not made. It further revealed the use and function of powerful discursive devices including the categorisation of people with learning disabilities as the same or different from other people with diabetes and the use of practice/principle rhetoric. Additionally, taking a discursive approach revealed that speakers (especially people with learning disabilities) can draw on socially available ideas around fairness, competence and the importance of self-management in diabetes care to construct people with learning disabilities as proactive, competent ‘diabetes patients’, challenging some dominant discourses and positionings of this population.

The views and experiences of all stakeholders on the topic of quality primary care diabetes appointments has so far been limited in the literature and the voices of healthcare professionals on the topic of diabetes care for people with learning disabilities have rarely been heard. A strength of this study is that it explored the accounts of different stakeholders in primary care diabetes for this population: people with learning disabilities, supporters and healthcare professionals. A further strength was in the advisory group involvement in the design of study documents, reflected in positive comments from advocacy group members who took part in the study and supported recruitment on the accessibility of recruitment documents and the benefits of visual prompts in making the project more inclusive.

There were some methodological limitations to this study. Despite including stakeholders from three groups, participants interviewed did not represent all stakeholders in diabetes primary care for this population. Prioritising the ethical merits of asking people with learning disabilities to identify people who support them in relation to diabetes appointments unintentionally restricted the diversity of supporters who were recruited and meant that no family carers were interviewed. In line with their presentation of themselves as independent during interviews, people with learning disabilities tended to report that they did not receive support in relation to appointments.
Although participants included people from a range of living and support settings, most participants had experience of self-advocacy so were used to considering and sharing their experiences. This meant the data were mainly from those with more practised communication skills who may have different experiences of appointments from those with more complex communication needs. Healthcare professionals were a small participant group mainly made up of people who expressed a particular interest in patients with learning disabilities. Different discourses and constructions of quality care may be found in the accounts of those who do not have a specific interest in this population.

Allowing people with learning disabilities the option to have someone they know present during interviews was an ethical strength and helped some people to feel comfortable speaking to the interviewer thereby enhancing the richness of the data. A downside to this was that having someone else present may have impacted on the information the person was happy to share. For example, where a member of staff was present, the speaker may have been reluctant to be critical of support staff. Use of visual prompts during interviews with people with learning disabilities was helpful in supporting understanding and prompting talk from people with learning disabilities as well as managing the discussion of sensitive topics. A possible disadvantage of the use of visual prompts was that they could prove distracting or gave the wrong impression that a short answer in response to looking at the card was all that was required. For example, participants sometimes gave a brief response to the prompt then put aside the card, viewing this as the end of discussion on that topic.

Limitations of interviewing ‘people with incomprehensible voices’ (Nunkoosing, 2005) have been raised in previous discourse analytic research with people with learning disabilities (Jingree, 2009). Despite gaining some rich data from this stakeholder group, in cases of communication difficulties obtaining analysable data was challenging. Interview data from three participants with learning disabilities had to be excluded from the analysis due to difficulty understanding their speech. This meant that the study focused on people with learning disabilities with relatively clearer speech. Additionally, for other people with learning disabilities, communication difficulties sometimes stilted the interview with the person simply agreeing with the supporter/interviewer when it was difficult to make themselves understood. Nevertheless, useful data was gained from these interviews and it could be considered a strength of the research that these individuals were not excluded.
8.4 Future Research

The findings from my thesis suggest numerous avenues for future research to improve understanding of diabetes/healthcare for people with learning disabilities. The use of video recordings of research interviews may support the inclusion of people with communication difficulties since it would allow consideration of facial expressions and body language and non-verbal gestures which are important in the communication of those who have difficulty with verbal communication. Analysis of video or audio recordings of clinical encounters would also enhance understanding of language in interaction in context. This would allow exploration of how the dilemmatic talk and dominant repertoires and positionings found in this research are played out during the medical encounter. Similarly, observation studies exploring whether/how professionals make decisions around reasonable adjustments and put these into practice and whether/how the goals set out in diabetes care quality standards are achieved in a naturally occurring setting would be valuable.

In terms of furthering knowledge of the social construction of quality care, it would be interesting to explore the concept of quality care for people with learning disabilities beyond diabetes care and see if similar or different issues arise. For example, whether care/appointment goals constructed as different for this population and inequalities accounted for in terms of practicalities talk and minimising distress in other areas of healthcare. It would be useful to explore the diabetes care journey where it is not always easily separated into primary and secondary care, medical or home environments.

This project focused on people with learning disabilities who had recent experience of diabetes primary care appointments. Investigation of the views and experience of people with learning disabilities on diabetes care who have stopped attending/frequently do not attend appointments may be enlightening. Additionally, the views of stakeholders on diabetes care quality whose voices did not appear in this study could usefully be explored including people from different ethnic groups, people with severe learning disabilities, and family carers.

Future research could usefully explore application of the knowledge gained from this research to diabetes education tools or tools aimed at improving the quality of the diabetes care encounter for people with learning disabilities and learning disability training for supporters and healthcare professionals. Some accounts during this study indicated that
healthcare professionals may be unaware of or do not make use of easy read diabetes resources aimed at people with learning disabilities. It would be useful to investigate awareness and use of these resources amongst diabetes care professionals. Given the complex and inconsistent application of legal requirements found in the accounts of supporters and healthcare professionals, exploration of awareness, understanding and application of the principles of reasonable adjustments and mental capacity for people with learning disabilities in the context of diabetes care (and other healthcare) would also be of value.

8.5 Conclusion

This thesis has furthered our understanding of the social construction of the concept quality care in relation to primary care diabetes appointments for adults with mild-to-moderate learning disabilities. Quality care was variously, flexibly and purposively constructed in talk. Broadly similar ideas and subtle differences in their uses by different stakeholders were identified. Differential repertoires drawn on by members of different stakeholder groups were also revealed. Stakeholders often drew on conflicting ideas which were subtly dealt with in ways which performed identity management and had implications for the types of activities that could be considered to constitute a good appointment or build complaint about quality of care. Responsibility for quality care was variously positioned with self and others, with speakers often positioning other stakeholders as responsible for care presented as poor or inadequate.

The ways in which quality care was constructed by stakeholders sometimes reflected discourses present in quality care guidelines and standards for diabetes care, policies for the improvement of healthcare for people with learning disabilities and the assumptions of previous quality assessments of diabetes care for people with learning disabilities (Diabetes UK, 2016a; Kachika, 2017; Taggart et al., 2012). These include the ideas that appointments should involve care processes such as blood tests and eye screening, that people with learning disabilities are entitled to independence and choice in their healthcare and that health/diabetes care should make reasonable adjustments to ensure equality of access and effectiveness of diabetes care for this population. Other prevalent repertoires appear to conflict with the existing guidance and research. Quality care could exclude care processes when they were impractical/may cause distress or were constructed as beyond the remit of
diabetes primary care appointments. Inconsistent discourses were drawn on around independence and choice which were important to uphold but offered within safe boundaries. This included complex employment of the principles of the Mental Capacity Act and informal assessments of capacity, often constructed as constraining quality care by necessitating the upholding of the legal rights of people with learning disabilities. The dominant repertoires revealed in this thesis and the ways in which some of these conflicting ideas were managed may contribute to the production and maintenance of inequalities in diabetes care for people with learning disabilities identified in previous research.

Further research is needed to continue to improve our understanding of these discourses and their implications for the health of people with learning disabilities and healthcare policy and practice for this population within diabetes care and beyond.
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Appendices

Appendix 1 – Examples of visual prompts

- **Check your blood sugar levels**
  (This is called HbA1c)

- **Get emotional support**
  For example, someone to talk to if you are feeling sad about diabetes

- **Get your blood pressure checked**

- **Have your feet checked**

- **Get specialist care if you are planning to have a baby**

- **Get advice about your diet**

(Images from Inspired Services Publishing)
Appendix 2 - Example of advisory group feedback on study documents

Further information about the project

Research project about Diabetes appointments for people with learning disabilities

Who is doing the project

• My name is Loma. I am a student at the Open University in Milton Keynes.
• I am looking for people to help me with my university project at the Open University.
• My project is supervised by Dr Liz Tilley.
• I am looking for people to take part in my university project.

What the project is about

• People who have diabetes have appointments to help them look after their diabetes.
• This is a meeting with a nurse or doctor to check on their diabetes.
• This project will look at what people with learning disabilities think is good and bad about their diabetes appointments.

If you want to help

• I will be talking to people about their diabetes appointments from June 2017.
• I will come and meet you. I will ask you questions about your diabetes appointments.
• I will record what we say. It will probably take about one hour.
• I want to know what you think. There are no right or wrong answers.
• Someone you know can stay with you when you talk to me.
• It is okay to say that you don’t want to answer a question.
• It is okay to say that you want to stop at any time.
• If I am worried about something you have said I will tell someone who supports you. I will talk to you about it first.

In order to assist participants with learning disabilities, illustrative images were included on the information and consent sheets which have been redacted due to copyright issues.
Appendix 3 - Recruitment advert – people with learning disabilities

Invitation to take part in a research project about diabetes appointments for people with learning disabilities

- My name is Lorna. I am a student at the Open University.
- I am looking for people to take part in my university project.

Who can help?
- I am looking for people with a learning disability who are:
  - Aged 18 or older
  - Have type 1 or type 2 diabetes

What the project is about
- People who have diabetes have appointments to help them look after their diabetes.
- This is a meeting with a nurse or doctor to check on their diabetes.
- This project will look at what people with learning disabilities think is good and bad about these appointments.
- This project is about diabetes appointment in primary care (primary care appointments are appointments usually at a clinic with the doctor or nurse not at the hospital).

If you want to take part
- Taking part in the project will involve being interviewed (talking to) me about what you think about your diabetes appointments.
- Someone you know can stay with you when you talk to me.
- I will be talking to people from January 2018 - April 2018.
- Travel expenses will be paid and you will be offered a £20 voucher as a thank you.

Someone who helps you
- I will ask you to tell me someone who helps you with your diabetes appointments. If they agree I will talk to them about how they help you with your diabetes appointments.
- You can still talk to me even if you don’t have someone who helps you with your appointments.

Contact details
- You can contact me to find out more about the project.
- You can ask me questions about the project.

Email: lorna.rouse@open.ac.uk  Phone: 07756099058
Faculty of Wellbeing, Education and Language Studies, 118 Horlock Building, The Open University, Walton Hall, Milton Keynes, MK7 6AA.

Appendix 4 - Participant Information Sheet – people with learning disabilities

Faculty of Wellbeing, Education and Language Studies
118, Horlock Building
The Open University
Walton Hall
Milton Keynes, MK7 6AA

Research project about

**Diabetes appointments for people with learning disabilities**

Who is doing the project

- My name is Lorna. I am a student at the Open University.
- My project is supervised by Dr Liz Tilley.
- I am looking for people to take part in my university project

What the project is about

- People who have diabetes have appointments to help them look after their diabetes.
- This is a meeting with a nurse or doctor to check on their diabetes.
- This project will look at what people with learning disabilities think is good and bad about these appointments.

What I want to do

- I want to interview (talk to) people with learning disabilities to find out what they think is good and bad about their appointments.

What to do if you think you might want to help

- Read the information and think about if you want to help.
- You can talk to other people to help you decide.
- You can ask me questions.
You can help if:

- You are aged 18 years or older.
- You have type 1 or type 2 diabetes.
- You have a learning disability.
- Your last diabetes appointment in primary care was less than three months ago (primary care appointments are appointments at a clinic with the doctor or nurse not at the hospital).

If you want to help

I will be talking to people about their diabetes appointments from June 2017 - December 2017.

- If you want to help I will come and meet you. I will ask you questions about your diabetes appointments.
- I will record what we say. It will probably take about one hour.
- I want to know what you think. There are no right or wrong answers.
- Someone you know can stay with you when you talk to me.
- It is ok to say that you don’t want to answer a question.
- It is ok to say that you want to stop at any time.
- If I am worried about something you have said I will tell someone who supports you. I will talk to you about it first.

Someone who helps you

- I will ask you to tell me someone who helps you with your diabetes appointments.
- If they want to help with the project I will talk to them about how they help you with your diabetes appointments.
- I will not tell them what you have said to me.
- You can still talk to me even if you don’t have someone who helps you with your appointments.
In order to assist participants with learning disabilities, illustrative images were included on the information and consent sheets which have been redacted due to copyright issues.
Appendix 5 - Invitation to participate – people with learning disabilities

Faculty of Wellbeing, Education and Language Studies
118, Hadlock Building
The Open University
Walton Hall
Milton Keynes, MK7 6AA

Invitation to participate text for emails/letters

Text for gatekeepers to participants with learning disabilities

Dear Care Manager/charity administrator,

My name is Lorna Rouse and I am a PhD student with the Open University (based in Cambridge). I am writing to ask for your help in finding people to take part in my research project. My project aims to improve understanding of the experience of primary care diabetes appointment for adults with learning disabilities. Although diabetes is more prevalent in people with learning disabilities, currently very little is known about the experience and views of people with learning disabilities on their primary care diabetes appointments.

As part of my project I am looking for adults with learning disabilities and type 1 or type 2 diabetes to take part in a one-to-one interview with me. I would be very grateful if you could circulate the attached information sheet to your staff and the people you support. Audio and hardcopy versions of the information for people with learning disabilities are available on request.

I am looking for adults (18+) with mild-to-moderate learning disability who:

- Have a diagnosis of type 1 or type 2 diabetes.
- Live in a community setting (independently, with family or in shared housing/supported living environment) in England.
- Have capacity to give informed consent to take part in the research.

Where possible I would also like to interview someone who supports the participant with a learning disability in relation to their diabetes care appointments.

The interview would take approximately 30 minutes to 1 hour, be tape recorded and would be arranged at a time and location convenient to participants. Shorter interviews can be arranged if more convenient. Someone they know can stay with participants with learning disabilities during the interview to help them to feel comfortable. Participation will be confidential so that identifying details will be known only to me. Any identifying details in the transcriptions such as names and places will be changed. Any travel expenses will be covered (but where possible I will travel to participants) and a £20 gift voucher will be offered in recognition of time given.

My project has received ethical approval from the Open University’s Human Research Ethics Committee. This project has also been reviewed and approved by Cambridgeshire County Council’s Research Governance Panel & Service Director for Adult Social Care.

I can be contacted for further information at: lorna.rouse@open.ac.uk, phone no. 07756099058 (project mobile), or at the address below. You can also see the study website for further information https://diabeteslearningdisabilities.wordpress.com/. I would be very happy to meet with anyone who would like to discuss or has any questions about my project.

Many thanks for your help.

Yours sincerely,

Lorna Rouse

IRAS ID: 216015 – Invitation to participate email/letter (learning disabilities) – v1.0 - May 2017
Appendix 6 - Participant Information Sheet – Supporters

Participant Information Sheet

Supporters

Further information about the research project:

Title of the project: Diabetes appointments for people with learning disabilities

IRAS ID: 216015   OU HREC Reference: HREC/2017/2522/Rouse/1

What is the aim of this research?

This study aims to improve understanding of the experience of diabetes care appointments for adults with mild-to-moderate learning disabilities, their supporters and healthcare professionals. This study will focus particularly on how ‘quality’ care is described in relation to primary care diabetes appointments for adults with learning disabilities.

Why this project?

• People with learning disabilities are more likely to be diagnosed with type 1 or type 2 diabetes than people without learning disabilities.

• Audits & surveys have so far provided a mixed picture of the quality of diabetes care for people with learning disabilities. These studies use varying definitions of ‘quality care’.

• No studies have explored what is considered a quality diabetes care appointment for people with learning disabilities by the key stakeholders in these appointments (e.g. diabetes patients with learning disabilities, those who support their diabetes management and healthcare professionals who provide diabetes care for adults with learning disabilities).

Invitation to participate

You are invited to participate in this research if you:

• Are aged 16+

• Have been identified by a participant with a learning disability as having provided some form of support in relation to their diabetes appointments (in a paid/professional or informal capacity e.g. as support worker, family carer, family member, friend) within the last 3 months.

What is meant by support?

Support may include attending the appointment and/or assisting with other activities relating to diabetes care appointments before, during or after the appointment. Therefore you may be considered to provide support even if you do not go into the appointment with the person you support. For example, support may be provided with: preparation for and travel to appointments and explaining and putting advice from healthcare professionals into practice after the appointment.

Please note that you can not participate in this study if the person you support does not wish to take part.

What should I do if I think I would like to take part?

• Read the rest of this Participant Information Sheet

• Contact the researcher expressing your interest and ask any questions you may have (contact details are provided at the end of this document).
Who is conducting the research and who is it for?
Lorna Rouse is carrying out this research as part of her PhD project funded by the Open University.

What will happen to the information I give?
Your interview will be audio recorded using a digital voice recorder. The audio recording will be typed into a transcript by the researcher who interviewed you. Any personal information given will be confidential to the research team. Anonymity will be maintained within the report so individuals are not identifiable. The researcher will then analyse your transcript and the transcripts of interviews from other people in the study and write a report for their PhD thesis. They may also write a paper and give presentations. The report, paper and presentations will contain anonymous quotes from the interviews. Therefore what you have said will be made public but your name will not. If you wish, we can send you a summary of findings from the research.

Your participation in the research project

Why am I being invited to participate in this research?
You have been invited to participate in this research because an adult with mild-to-moderate learning disability who has agreed to participate in this study has told us that you support them with their primary care diabetes appointments.

Please note that you can not participate in this study if the person you support does not wish to take part.

Whether I can refuse to take part
Participation is entirely voluntary; you do not have to take part. You can refuse to take part in this study at any time before during or after the study up until the final report has been written. Your choice to participate will not impact on you job or the care of the person you support.

Whether I can withdraw at any time, and how
You are free to withdraw from this project at any time until the final report has been written (predicted to be December 2018) without explaining the reasons why. If you decide to withdraw from the study your interview (audio file and transcript) and any other information relating to your involvement in the study will be destroyed.

To withdraw you can: talk to the researcher before, during or after the interview, contact the researcher by phone or email (contact details below), complete and return the withdrawal slip attached to the consent form.

If I take part in this research, what will be involved?
One-to-one interviews will be conducted during June 2017-December 2017. The interviews will take approximately 30 minutes to 1 hour and would be conducted at your workplace or another location (e.g. community venue) if you prefer, at a date and time that is convenient to you. To ensure your safety, all our researchers carry photographic identification. Reimbursement will be available for reasonable travel expenses to interview venues. Travel expenses will be paid at 37.5 pence per mile or public transport rates. All claims must be accompanied by relevant receipts.

IRAS ID: 216015  -  HREC/2017/2523/Rouse/1 - Participant Information Sheet (Supporters)  -  v1.0  -  April 2017
What will the interview be like?
If you agree to take part the researcher will arrange a convenient time and place to meet with you and carry out an interview. The interview will be about your experience of providing support relating to primary care diabetes appointments to an adult who has mild-to-moderate learning disabilities. We want to hear about your views in your own words so although the interview will be guided by a schedule there will be no set questions and answers and there are no right or wrong answers. The interview will last for around 30 minutes to 1 hour and will be audio recorded using a digital voice recorder. This will allow you to talk in-depth about your experiences.

What will we be talking about?
We are interested in your experience of all aspects of providing support to an adult who has mild-to-moderate learning disabilities relating to their primary care diabetes appointments, including before, during and after the appointments.

The kinds of topics we will be asking you about include: your experiences of making preparations for appointments, your experiences of communicating with healthcare professionals, your views on what makes a good/poor quality appointment for adults with learning disabilities.

Is it confidential?
Your participation will be treated in strict confidence in accordance with the Data Protection Act. No personal information will be passed to anyone outside the research team. The researcher will write a report of the findings from this study, but no individual will be identifiable in published results of the research.

Confidentiality would only be broken if you are at serious risk of harming yourself or others then we will have to share your information with appropriate agencies, this may be without your permission. In this unlikely event we would discuss it with you first.

How your participation in the project will be kept confidential
In order to protect your anonymity your name and the names of any people or places you mention will be changed when your interview is transcribed. This means that your name will only be known to the researcher who interviews you. Any information which may make you easy to identify will also be changed e.g. your workplace. Your name will not be connected to any information stored for the project. The interview transcript will be seen by the researcher and their supervisors at The Open University. Electronic and hardcopy files relating to your interview will be stored securely. Once the project has been completed the audio recording of your interview will be destroyed.

Whether there are any risks involved (e.g. side effects from taking part) and if so what will be done to ensure your wellbeing/safety
A potential risk involved in taking part in this study is that it is possible you may find talking about some experiences upsetting. If this happens you can:

• tell the interviewer that you would like to take a break at any time
• choose not to answer any questions without giving an explanation
• stop the interview without giving an explanation.
Taking part in the interview may also raise questions you have about diabetes care and/or supporting someone with learning disabilities to manage diabetes. You will be offered contact details of organisations that can provide information and support on these topics.

**Whether there are any benefits from taking part**

There are no direct benefits to you of taking part but the study may help to improve understanding of diabetes care appointments for people with learning disabilities.

**What happens now?**

You should take at least 24 hours to consider whether you would like to take part in this study and discuss your decision with other people if you wish. Please contact the researcher using the contact details below if you think you would like to take part in the study. The researcher will ask you a few questions about yourself. Your participation is entirely voluntary. If you have any questions about the study I would be very happy to answer them.

**Contact details**

If you have any questions or would like any further information about the study please use the contact details below to get in touch with the researcher Lorna Rouse.

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Project Supervisor</th>
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<tbody>
<tr>
<td>Lorna Rouse</td>
<td>Dr Elizabeth Tilley</td>
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<tr>
<td>Faculty of Wellbeing, Education and Language Studies</td>
<td>Faculty of Wellbeing, Education and Language Studies</td>
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<tr>
<td>118, Horlock Building</td>
<td>118, Horlock Building</td>
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<td>The Open University</td>
<td>The Open University</td>
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<tr>
<td>Walton Hall</td>
<td>Walton Hall</td>
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<tr>
<td>Milton Keynes, MK7 6AA</td>
<td>Milton Keynes, MK7 6AA</td>
</tr>
<tr>
<td>Email: <a href="mailto:lorna.rouse@open.ac.uk">lorna.rouse@open.ac.uk</a></td>
<td>Email: <a href="mailto:elizabeth.tilley@open.ac.uk">elizabeth.tilley@open.ac.uk</a></td>
</tr>
<tr>
<td>Project mobile: 07756099068</td>
<td>Phone: 01908654283</td>
</tr>
</tbody>
</table>

You will be given a copy of this information sheet to keep.
Appendix 7 - Invitation to participate – Healthcare professionals

Faculty of Wellbeing, Education and Language Studies
116, Harlock Building
The Open University
Walton Hall
Milton Keynes, MK7 6AA

Dear Practice Manager

My name is Lorna Rouse and I am a PhD student with the Open University (based in Cambridge). I am writing to ask for your help in finding people to take part in my research project exploring primary care diabetes appointments for adults with learning disabilities. Research indicates that both type 1 and type 2 diabetes are more prevalent in people with learning disabilities. Currently, very little is known about healthcare professionals’ experience and views of diabetes primary care provision for this population. My research aims to improve understanding of this topic.

As part of my project I am looking for primary care practitioners with experience of providing diabetes care services to adults with learning disabilities to take part in a one-to-one interview with me. I would be very grateful if you could circulate the attached advert and participant information sheet to members of your diabetes care team.

The interview would take around 30 minutes to 1 hour, be tape recorded and would be arranged at a time and location convenient to participants. Participation will be confidential so that identifying details will be known only to me. Any identifying details in the transcriptions such as names and places will be replaced with pseudonyms. Any travel expenses will be covered. Interviews can be arranged via Skype/phone if preferred.

I am looking for healthcare professionals (e.g. GP, diabetes nurse, healthcare assistant, community nurse, learning disability nurse) who have provided primary care diabetes care services for adult(s) with mild-to-moderate learning disabilities and are located within Cambridgeshire & Peterborough CCG geography.

This research has been reviewed by, and received a favourable opinion, from the Open University’s Human Research Ethics Committee - HREC reference number: HREC/2017/2522/Rouse/1 (http://www.open.ac.uk/research/ethics/), Cambridgeshire & Peterborough CCG and the NHS Health Research Authority - IRAS ID: 216015 (see attached letter of approval).

I can be contacted for further information at: lorna.rouse@open.ac.uk, phone no. 07756099058 (project mobile), or at the above address. You can also find further information about the project at https://diabeteslearningdisabilities.wordpress.com/. I would be very happy to meet with any members of the care team who would like to discuss or have any questions about my project.

Many thanks for your help.

Yours sincerely

Lorna Rouse

Lorna Rouse
Postgraduate Student
Faculty of Wellbeing, Education and Language Studies
116, Harlock Building
The Open University
Walton Hall
Milton Keynes, MK7 6AA
lorna.rouse@open.ac.uk
07756099058

IRAS ID: 216015 – Invitation to participate email/letter (healthcare professionals) – v1.0 - May 2017
HREC/2017/2522/Rouse/1
Appendix 8 - Participant information sheet – Healthcare Professionals

Faculty of Wellbeing, Education and Language Studies
118, Horlock Building
The Open University
Walton Hall
Milton Keynes, MK7 6AA

Further information about the research project:

Title of the project: Diabetes appointments for people with learning disabilities

IRAS ID: 216015
OU HREC Reference: HREC/2017/2522/Rouse/1

What is the aim of this research?
This study aims to improve understanding of the experience of diabetes care appointments for adults with mild to moderate learning disabilities, their supporters and healthcare professionals. This study will focus particularly on how ‘quality’ care is described in relation to primary care diabetes appointments for adults with learning disabilities.

Why this project?
- People with learning disabilities are more likely to be diagnosed with type 1 or type 2 diabetes than people without learning disabilities.
- Audits & surveys have so far provided a mixed picture of the quality of diabetes care for people with learning disabilities. These studies use varying definitions of ‘quality care’.
- No studies have explored what is considered a quality diabetes care appointment for people with learning disabilities by the key stakeholders in these appointments (e.g. diabetes patients with learning disabilities, those who support their diabetes management and healthcare professionals who provide diabetes care for adults with learning disabilities).

Invitation to participate
You are invited to participate in this research if:
- Have been involved in the provision of diabetes care services for a patient with mild to moderate learning disabilities within the last 3 months.
- Have provided this support located within a CCG geography.

What should I do if I think I would like to take part?
- Read the rest of this Participant Information Sheet
- Contact the researcher expressing your interest and ask any questions you may have (contact details are provided at the end of this document).
Who is conducting the research and who is it for?
Lorna Rouse is carrying out this research as part of her PhD project funded by the Open University.

What will happen to the information I give?
Your interview will be audio recorded using a digital voice recorder. The audio recording will be typed into a transcript by the researcher who interviewed you. Any personal information given will be confidential to the research team. Anonymity will be maintained within the report so individuals are not identifiable. The researcher will then analyse your transcript and the transcripts of interviews from other people in the study and write a report for their PhD thesis. They may also write a paper and give presentations. The report, paper and presentations will contain anonymous quotes from the interviews. Therefore what you have said will be made public but your name will not. If you wish, we can send you a summary of findings from the research.

Your participation in the research project

Why am I being invited to participate in this research?
You have been invited to participate in this research because you have told us that you are part of a diabetes care team that provides diabetes primary care services to at least one adult with mild-to-moderate learning disabilities. For example, this may be through your role as a diabetes nurse, GP or healthcare assistant.

Whether I can refuse to take part
Participation is entirely voluntary; you do not have to take part. You can refuse to take part in this study at any time before during or after the study up until the final report has been written. Your choice to participate will not impact on you job.

Whether I can withdraw at any time, and how
You are free to withdraw from this project at any time until the final report has been written (predicted to be December 2018) without explaining the reasons why. If you decide to withdraw from the study your interview (audio file and transcript) and any other information relating to your involvement in the study will be destroyed.

To withdraw you can: talk to the researcher before, during or after the interview, contact the researcher by phone or email (contact details below), complete and return the withdrawal slip attached to the consent form.

If I take part in this research, what will be involved?
One-to-one interviews will be conducted during June 2017-December 2017. The interviews will take approximately 30 minutes to 1 hour and would be conducted at your workplace or another location (e.g. community venue) if you prefer, at a date and time that is convenient to you. To ensure your safety, all our researchers carry photographic identification. Reimbursement will be available for reasonable travel expenses to interview venues. Travel expenses will be paid at 37.5 pence per mile or public transport rates. All claims must be accompanied by relevant receipts.
What will the interview be like?
If you agree to take part the researcher will arrange a convenient time and place to meet with you and carry out an interview. The interview will be about your experience of providing diabetes care to someone who has mild-to-moderate learning disabilities within primary care settings. We want to hear about your views in your own words so although the interview will be guided by a schedule there will be no set questions and answers and there are no right or wrong answers. The interview will last for around 30 minutes to 1 hour and will be audio recorded using a digital voice recorder. This will allow you to talk in-depth about your experiences.

What will we be talking about?
We are interested in your experience of all aspects of providing diabetes care to people with learning disabilities in primary care including before, during and after the appointments.

The kinds of topics we will be asking you about include: your experiences of making preparations for appointments, your experiences of communicating with people with learning disabilities and their carers, your views on what makes a good/poor quality appointment for adults with learning disabilities.

Is it confidential?
Your participation will be treated in strict confidence in accordance with the Data Protection Act. No personal information will be passed to anyone outside the research team. The researcher will write a report of the findings from this study, but no individual will be identifiable in published results of the research.

Confidentiality would only be broken if you are at serious risk of harming others then we will have to share your information with appropriate agencies, this may be without your permission. In this unlikely event we would discuss it with you first.

How your participation in the project will be kept confidential
In order to protect your anonymity your name and the names of any people or places you mention will be changed when your interview is transcribed. This means that your name will only be known to the researcher who interviews you. Any information which may make you easy to identify will also be changed e.g. your workplace. Your name will not be connected to any information stored for the project. The interview transcript will be seen by the researcher and their supervisors at The Open University. Electronic and hardcopy files relating to your interview will be stored securely. Once the project has been completed the audio recording of your interview will be destroyed.

Whether there are any risks involved (e.g. side effects from taking part) and if so what will be done to ensure your wellbeing/safety
A potential risk involved in taking part in this study is that it is possible you may find talking about some experiences upsetting. If this happens you can:

- tell the interviewer that you would like to take a break at any time
- choose not to answer any questions without giving an explanation
- stop the interview without giving an explanation.
Whether there are any benefits from taking part
There are no direct benefits to you of taking part but the study may help to improve understanding of diabetes care appointments for people with learning disabilities.

What happens now?
You should take at least 24 hours to consider whether you would like to take part in this study and discuss your decision with other people if you wish. Please contact the researcher using the contact details below if you think you would like to take part in the study. The researcher will ask you a few questions about yourself. Your participation is entirely voluntary. If you have any questions about the study I would be very happy to answer them.

Contact details
If you have any questions or would like any further information about the study please use the contact details below to get in touch with the researcher Lorna Rouse.

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Project Supervisor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lorna Rouse</td>
<td>Dr Elizabeth Tilley</td>
</tr>
<tr>
<td>Faculty of Wellbeing, Education and Language Studies 118, Horlock Building</td>
<td>Faculty of Wellbeing, Education and Language Studies 118, Horlock Building</td>
</tr>
<tr>
<td>The Open University</td>
<td>The Open University</td>
</tr>
<tr>
<td>Walton Hall</td>
<td>Walton Hall</td>
</tr>
<tr>
<td>Milton Keynes, MK7 6AA</td>
<td>Milton Keynes, MK7 6AA</td>
</tr>
<tr>
<td>Email: <a href="mailto:lorna.rouse@open.ac.uk">lorna.rouse@open.ac.uk</a></td>
<td>Email: <a href="mailto:elizabeth.tilley@open.ac.uk">elizabeth.tilley@open.ac.uk</a></td>
</tr>
<tr>
<td>Project mobile: 07756099058</td>
<td>Phone: 01980654283</td>
</tr>
</tbody>
</table>
Appendix 9 - Examples of social media and website recruitment

Website

Website recruitment form

Facebook page

Twitter
Appendix 10 - Hardcopy expression of interest form

Contact Form

I would like to find out more about the project diabetes appointments for people with learning disabilities.

I would prefer to be contacted by

[ ] Email [ ] Phone [ ] Post

Name: ____________________________________________

I would prefer you to contact someone who supports me

Name of someone who supports me: ___________________________

Phone no: ___________________

Email: ___________________

Address: _____________________________________________

_____________________________________________________

_____________________________________________________

_____________________________________________________

Please return this form in the stamp addressed envelope attached or to:

Lorna Rouse, Faculty of Wellbeing, Education and Language Studies,118, Horlock Building, The Open University, Walton Hall, Milton Keynes, MK7 6AA.


In order to assist participants with learning disabilities, illustrative images were included on the information and consent sheets which have been redacted due to copyright issues.
Appendix 11 - Appointment reminder card

Appointment Card for interview about diabetes appointments for people with learning disabilities

Project title: Diabetes appointments for people with learning disabilities
Name:
Interview date:
Interview time:
Interview location:
Interviewer name:
Interviewer phone number:

Picture of a clock showing appointment time.
Appendix 12 - Interview Schedule for people with learning disabilities

Interview Schedule – learning disabilities

Introduction

For my university project I want to know what diabetes appointments are like for people with learning disabilities. The appointments I’m interested in are primary care diabetes appointments. Primary care means appointments that don’t happen in hospital (for example, appointments with the doctor or nurse at your GP surgery). I will ask you some questions about what happens before, during and after your diabetes appointments. I will ask some questions about what you think about your appointments. There are no right or wrong answers to these questions. I have brought some pictures with me of things that might happen at diabetes appointments to help remind you about your appointments. We can look at these to help you remember.

General/warm-up questions
When was your last diabetes appointment?

Who was your last diabetes appointment with?

Do you know when your next diabetes appointment is?

How good do you think your diabetes appointments are?

Experience of appointments

Before
First we will talk about things that happen before your appointment.

I’d like to start by asking you about how you make your diabetes appointments (e.g. with your doctor/nurse).

How do you know that your appointment is due/that you need to make an appointment?
(e.g. your last appointment, reminders/contact from surgery/health services, reminder from supporter, regular appointment)

Who makes your diabetes appointments?
(You, supporter, surgery/health services, LD nurse, healthcare facilitator)

How do you make an appointment?
(post, forms, phone, online, going into the surgery, through the receptionist at the end of previous appointment)

How easy/difficult is it to make appointments?
(getting in touch with surgery, finding a convenient time, communication, accessibility of forms/letters, phone/online systems)

Do you have any help to make appointments?

Who helps? What do they do? What do you do?
How do you/your supporter cancel and rearrange appointments if you need to?
(post, forms, phone, online, going into the surgery)

How easy/difficult is it to cancel/rearrange appointments?
(can you give me an example of when it has been easy/difficult? Your last/next appointment)

What has stopped you from making an appointment?
(e.g. difficulties communicating with receptionists/healthcare services, problems with phone/online system, not knowing appointment was due/necessary. Can you give me an example?)

Now I’m going to ask you about any information you are given about your appointment.

Before an appointment, what information are you given about:
- What the appointment is for?
- Why the appointment is necessary?
- When the appointment will be?
- Where the appointment will be?
- What will happen when you get there?
- Anything you need to bring?
(format e.g. letters, phone call)

How easy is the information you are given about your appointment to understand?

Is there any information you don’t get that you would like/would be useful?

Now we’re going to talk about how you prepare for your appointments

How do you make sure you remember your appointments?
(support, reminders from practice, diary, calendar)

Do you write down questions you want to ask during the appointment?
(Where do you write them? What kinds of questions? Can you give me an example?)

Do you make arrangements for someone to support you when you attend your appointment?
(For example, if they can make the appointment, where you will meet, how they will support you.)

Do you talk to your doctor/nurse/surgery about any help you might need during the appointment?
(For example, if you have a needle phobia, if you find it difficult to wait in crowded places, if you find it helpful to meet a new nurse/doctor before the appointment, if you need to have a longer appointment.)

Do you prepare anything to take with you? (For example, care plan, samples, note book, records e.g. of blood sugar levels, comforter.)

Does anyone help you to prepare for appointments/with any of the above? Who? How do they help? (e.g. care, family member, healthcare facilitator, someone from your surgery)

Is there anything else you do to prepare for your diabetes appointment?
Now I’d like to ask you about travelling to your appointment.

Where do your appointments take place?

How do you get there?

What plans do you make before you travel?
*(For example, arrange for a lift, plan public transport route, parking space, arrange transport through health services/health facilitators)*

Does anyone support you to travel to your appointments? Who? How do they help?
*(What do you do, what does your supporter do, what does the hcp/clinic do?)*

What is easy/difficult about travelling to your appointments?

*Now I’d like to ask some questions about when you arrive/first get to the appointment.*

Have you had any difficulty getting into the building?
*(e.g. lack of ramps, difficulty with steps)*

How do you know where to go when you arrive?
*(e.g. signs, supporter, info. received before appointment e.g. letter, map)*

How do you book in/let them know you have arrived?
*(talk to receptionist, electronically, supporter: books in)*

How easy do you find booking in?
*(easy, difficult, confusing)*

What is the waiting area like?
*(e.g. where, seating, comfortable/uncomfortable, things to do)*

How long do you have to wait?

Does someone wait with you? Who? What do they do?

What has stopped you from getting to an appointment?
*(e.g. transport problems, difficulties accessing the building, problems finding support, anxiety, can you give me an example)*

*During*

*Now we will talk about what happens during your appointment.*

Diabetes checks/care processes (with visual prompts/cue cards)

Which of these checks have you had?
*(visual prompts include: blood glucose, blood pressure, cholesterol, eyes, feet, kidneys, weight, smoking, care plan, education course, pregnancy planning, specialists, emotional/psychological support)*

Can you tell me about what happens when you have this check?

What do you find easy/difficult or good/bad about this check?
How do you feel after the appointment?
(e.g. after your last appointment - happy, relieved, confused, worried, confident)

Do you ever talk to other people about how the appointment went? Who do you talk to? Why?
(pactical support, moral support)

How easy is it to follow any advice you were given during your appointment? For example, remembering advice, making changes that your doctor/nurse has suggested to your medication, diet, exercise, monitoring sugar levels.
(e.g. after your last appointment, can you give me an example of when it was easy/difficult?)

Does anyone help you with this? Who? How do they help?

Does your doctor/nurse do anything for you after the appointment? (e.g. order equipment, refer you to other healthcare services, find information for you, discuss medication. Can you give me an example?)

Do you/your supporter contact your doctor/nurse if you have questions when you are at home?
(who, how, can you give me an example?)

Did going to your last appointment change how you look after your diabetes in any way? How?
(e.g. medication use, diet, activity, can you give me an example?)

Quality/value
Now I'd like to ask some questions about how good you think your appointments are.

What is helpful/useful about diabetes appointments?

Do your appointments help you to learn about diabetes and how to look after it? For example, do appointments help you to learn about:
diet and exercise
how/when to take medication
how to balance blood sugar levels
how to use equipment (e.g. blood testing kit, inject insulin, hypo kit)
(How do they help? can you give me an example)

Do your appointments help you to answer questions you have about diabetes?
(How? can you give me an example)

Do appointments help you to feel confident about looking after your diabetes?
(How? can you give me an example)

Is there anything else that's helpful/useful about appointments?

What is difficult about your appointments?
(inconvenient, frustrating, boring, scary)

Can you tell me what would improve your appointments?
Does anyone help you when you are having this check? Who? How do they help?

How could this check be improved?

(e.g. how could your last experience have been better; what could be done differently?)

Communication

How easy do you find talking to the doctor/nurse about your diabetes?

How easy do you find it to ask questions during appointments?

Does the doctor/nurse answer any questions you ask during the appointment?

How easy do you find understanding what the doctor/nurse says during appointments?

Do anyone come into the appointment with you or do you go in on your own? Who?

Do they help you to talk to the doctor/nurse about your diabetes? What do they do? How do they help?

Do you always agree/ever disagree with what your supporter says at your appointment about your diet?, Exercise?, Medication?, Anything else?

(can you give me an example of when you have disagreed?)

How easy do you find it to understand any information your doctor/nurse gives you during the appointment about: Medication?, Results of check-ups/tests?, Diet?, Exercise? Anything else?

(examples, information format verbal, written)

Do you always agree/ever disagree with the advice your doctor/nurse gives you? For example, about medication, diet, exercise?

Accessibility

Have you ever had any difficulties getting into the doctor’s/nurse’s office?

(what, any way this could be improved)

Have you ever had any problems using equipment during the appointment? For example, scales, eye screening equipment.

(what, any way this could be improved, made easier)

Does your doctor/nurse use jargon or words you don’t understand?

(can you give me an example?)

How well does your doctor/nurse explain difficult ideas or information about diabetes?

Does anyone help you to understand difficult ideas/information during appointments? Who? How do they help?

After

Now we’re going to talk about what happens after your appointment.
What do you think makes a good/bad appointment?

If you were telling your doctor/nurse how to make your appointment good, what would you tell them?

**Responsibility**

I am interested in knowing what you think about who is responsible/whose job it is to make sure that diabetes appointments are good quality.

Whose responsibility/job is it to make sure that you can get to your appointments? *For example, who should make sure that:*

- it is easy for you/your supporter to make appointments
- you have information that you can understand about your appointment
- you can travel to your appointment

Whose responsibility/job is it to make sure that your appointments are accessible/that you get any changes/support you need to help you during the appointment? *For example, who should make sure that:*

- the doctor/nurse/surgery knows about any help you might need when you are at the appointment?
- that you can use any equipment
- that it is easy to understand what the doctor/nurse says

Whose responsibility/job is it to make sure that you can follow advice and get any help you need after the appointment? *For example, who should make sure that:*

- that you can remember/follow advice that you were given during the appointment
- that you can contact someone (doctor/nurse) if you have any questions after the appointment.

**Other**

Is there anything else you’d like to tell me about your diabetes appointments?

Thank you for your help.
Appendix 13 - Consent form – People with learning disabilities

In order to assist participants with learning disabilities, illustrative images were included on the information and consent sheets which have been redacted due to copyright issues.
I understand that anything I say will only be used for research.

I understand that my information will be stored safely.

Your name (print) ...........................................

Your Signature .............................................

Date ..............................................

Name of researcher (print) ..............................

Signature ..............................................

Date ..............................................

Please tick this box if you would like to be sent a summary of the project’s findings. □

YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP
Withdrawal Form

Please keep this form in case you change your mind about me using your answers in the project.

If you don't want your answers to be used in the project please sign this form or tick the box and send it to:
Lorna Rouse
Faculty of Wellbeing
Education and Language Studies
118, Horlock Building
The Open University
Walton Hall
Milton Keynes, MK7 6AA.
Please send it before 31st December 2017.

Title of Project:
Quality of diabetes care appointments for people with learning disabilities

I WISH TO WITHDRAW FROM THIS STUDY

Your name: ______________________

Signed: _________________________  Date: _________________________
Appendix 14 - Resources sheet – version 1

Where to find information and help about diabetes

Information about diabetes

Diabetes UK

You can find information about diabetes on the Diabetes UK website
https://www.diabetes.org.uk/

Diabetes UK Helpline

The Diabetes UK Helpline provides specialist information and advice on living with diabetes. This is a support helpline for anyone with diabetes, their friends, family and carers.

You can contact the Diabetes UK helpline by:

Phone: 0345 123 2399, Monday to Friday, 9am-7pm

Email: helpline@diabetes.org.uk

Post:

Diabetes UK Helpline
Wells Lawrence House
126 Back Church Lane
London
E1 1FH

You can find information about this helpline on the Diabetes UK website
https://www.diabetes.org.uk/How_we_help/Helpline/

Screenshot of Diabetes UK website
Information about diabetes for people with learning disabilities

*Diabetes UK*

**Resources for people with learning disabilities**

You can find information about diabetes care for people with learning disabilities aimed at people with learning disabilities and their carers on the Diabetes UK website. This includes an easy read guide to type 2 diabetes.


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*Northern Health Trust*

**Pictorial information about type 2 diabetes for people with a learning disability**

This booklet is about type 2 diabetes and is aimed at people with learning disabilities. It can be downloaded from the Northern Health Trust website

http://www.northerntrust.hscni.net/pdf/Diabetes_booklet_for_those_with_a_learning_difficulty.pdf. For a hardcopy contact: Jillian Scott, Health Care Facilitator Learning Disability Team Rathleia House Mountfern Complex 8a Rugby Avenue Coleraine BT52 1JL.
Information about diabetes for people with learning disabilities

**Diabetes UK**

Resources for people with learning disabilities

You can find information about diabetes care for people with learning disabilities aimed at people with learning disabilities and their carers on the Diabetes UK website. This includes an easy read guide to type 2 diabetes.


**Northern Health Trust**

Pictorial information about type 2 diabetes for people with a learning disability

This booklet is about type 2 diabetes and is aimed at people with learning disabilities. It can be downloaded from the Northern Health Trust website

http://www.northerntrust.hscni.net/pdf/Diabetes_booklet_for_those_with_a_learning_difficulty.pdf. For a hardcopy contact: Jillian Scott, Health Care Facilitator Learning Disability Team Rathlea House Mountfern Complex 8b Rugby Avenue Coleraine BT52 1JL.
**Easy Health**

*Easyhealth.org.uk* has some easy read information about diabetes that can be downloaded from [http://www.easyhealth.org.uk/listing/diabetes-%28leaflets%29](http://www.easyhealth.org.uk/listing/diabetes-%28leaflets%29)

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**Queensland Centre for Intellectual and Developmental Disability**

Public Health England

Making Reasonable Adjustments to Diabetes Services for People with Learning Disabilities is a report about changes that have been made to diabetes services to make them easier for people with learning disabilities to use. You can download this report from Public Health England:

http://www.improvinghealthandlives.org.uk/publications.php?id=1176&edit

Support for carers

The National Family Carer Network provides support to family carers supporting a person with a learning disability http://www.familycarers.org.uk/

email: info@familycarers.org.uk
Appendix 15 - Letter of approval Open University HREC

**Human Research Ethics Committee (HREC)**

From: Dr. Duncan Banks, Deputy Chair  
The Open University Human Research Ethics Committee

Email:  
Extension:  

To: Lorna Rouse, WELS

Project title: The social construction of quality diabetes care appointments in primary care by adults with mild-to-moderate learning disabilities, their supporters and healthcare professionals.

HREC ref: HREC/2017/2522/Rouse/1  
AMS ref:  

**Memorandum**

Date application submitted: 31/08/17  
Date of HREC response: 31/08/17

This memorandum is to confirm that the research protocol for the above-named research project, as submitted to the OU HREC for ethics review, has been given a favourable opinion by the HREC review panel.

Please note the following:

1. You are responsible for notifying the HREC immediately of any information received by you, or of which you become aware which would cast doubt on, or alter, any information contained in the original application, or a later amendment which would raise questions about the safety and/or continued conduct of the research.

2. It is essential that any proposed amendments to the research are sent to the HREC for review, so they can be recorded and a favourable opinion given prior to any changes being implemented (except only in cases of emergency when the welfare of the participant or researcher is or may be affected).

3. Please include your HREC reference number in any documents or correspondence, also any publicity seeking participants or advertising your research, so it is clear that it has been reviewed by HREC and adheres to OU ethics review processes.

4. You are authorised to present this memorandum to outside bodies such as NHS Research Ethics Committees in support of any application for future research clearance. Also, where there is an external ethics review, a copy of the application and outcome should be sent to the HREC.

5. OU research ethics review procedures are fully compliant with the majority of grant awarding bodies and where they exist, their frameworks for research ethics.

6. At the conclusion of your project, by the date you have stated in your application, you are required to provide the Committee with a final report to reflect how the project has progressed, and importantly whether any ethics issues arose and how they were dealt with. A copy of the final report template can be found on the research ethics website - [http://www.open.ac.uk/research/ethics/human-research/human-research-ethics-full-review-process-and-proforma#final_report](http://www.open.ac.uk/research/ethics/human-research/human-research-ethics-full-review-process-and-proforma#final_report)

Best regards,

Dr. Duncan Banks, Deputy Chair, The Open University Human Research Ethics Committee  
[http://www.open.ac.uk/research/ethics/](http://www.open.ac.uk/research/ethics/)  
March 2015
Appendix 16 - Letter of approval Health Research Authority

Miss Lorna Rouse  
Faculty of Wellbeing, Education and Language Studies  
118, Horlock Building, The Open University  
Walton Hall, Milton Keynes  
MK7 6AA  

30 August 2017  

Dear Miss Rouse

Letter of HRA Approval

Study title: The social construction of quality diabetes care appointments in primary care by adults with mild-to-moderate learning disabilities, their supporters and healthcare professionals.

IRAS project ID: 216015

Sponsor: The Open University

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read Appendix B carefully, in particular the following sections:

- Participating NHS organisations in England – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities.
- Confirmation of capacity and capability - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.
Appendix 17 – Letter of approval from local R&D

Dear Lorna,

Re: IRAS-216015

Acknowledgement of study in GP practices in:

Full Study Title: L01611. (IRAS-216015) Diabetes care appointments for adults with learning disabilities v1

This email confirms the research office has registered the above referenced study for information and we are happy for you to approach practices within the above localities if needed. Please ensure the HRA Approval letter is forwarded to practices. N.b. Please note this confirmation only relates to recruitment of GP staff for semi-structured interviews.

Once your study has completed, we would be grateful if you could forward a copy of the final report, a one-page lay summary and any publications associated with the study to:...

...

Kind regards.
Appendix 18 - Letter of approval Council

Dear Lorna,

Date: 22/11/2017

Thank you for your research application (reference number; 171026 LR) regarding the study entitled “The social construction of quality diabetes care appointments in primary care by adults with mild-to-moderate learning disabilities, their supporters and healthcare professionals.”

Your application has been assessed to be a Level 2 research proposal for the following reasons:

- Ability to withdraw
- Anonymity of results

The application has been reviewed by the Research Governance Panel & Service Director for Adult Social Care, and I am pleased to inform you that your application has been approved.

Kind regards,
### Appendix 19 - Transcription notes

<table>
<thead>
<tr>
<th>Symbol</th>
<th>Usage</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>( ( )</td>
<td>additional information on speech, interview context or content.</td>
<td>((puts on angry voice/nods head/GP surgery/staff enters the room))</td>
</tr>
<tr>
<td>( )</td>
<td>Non-word sounds</td>
<td>(laughs)</td>
</tr>
<tr>
<td>[ ]</td>
<td>Indicates overlapping in speech.</td>
<td></td>
</tr>
<tr>
<td>Underline</td>
<td>Indicates emphasised speech.</td>
<td></td>
</tr>
<tr>
<td>CAPS</td>
<td>Indicates speech that is noticeably louder than surrounding speech.</td>
<td></td>
</tr>
<tr>
<td>“word”</td>
<td>Indicates noticeably quieter than surrounding speech.</td>
<td></td>
</tr>
<tr>
<td>-</td>
<td>Indicates unfinished/interrupted word or sentence.</td>
<td></td>
</tr>
<tr>
<td>hhh</td>
<td>Indicates sighing/audible breathing out.</td>
<td></td>
</tr>
<tr>
<td>.hhh</td>
<td>Indicates audible intake of breath.</td>
<td></td>
</tr>
<tr>
<td>(word)</td>
<td>Word that is unclear/unsure of in the transcription.</td>
<td></td>
</tr>
<tr>
<td>(word)/(word)</td>
<td>Indicates two equally possible alternative hearings of an unclear word.</td>
<td></td>
</tr>
<tr>
<td>Symbol</td>
<td>Description</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>-----------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>()</td>
<td>Speech that the transcriber could not recognise. Size of space indicates length of missing speech.</td>
<td></td>
</tr>
<tr>
<td>‘speech’</td>
<td>Indicates speaker is reporting speech of self or others.</td>
<td></td>
</tr>
<tr>
<td>=</td>
<td>Indicates latching – one section of talk is immediately followed by the next with no space in between.</td>
<td></td>
</tr>
<tr>
<td>.</td>
<td>Short pause</td>
<td></td>
</tr>
<tr>
<td>(pause)</td>
<td>Long pause</td>
<td></td>
</tr>
<tr>
<td>[...]</td>
<td>Text removed/Long section of off topic talk not transcribed.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 20 - Organisation of repertoires in NVivo – supporters

Nodes

- **Supporter repertoires**
  - Support is needed for times of change or problems only
  - Pwld should have independence and choice
  - Pwld should be the focus of the appointment
  - Pwld are the same as other people
  - Pwld are different from other diabetes patients
  - Pwld are dependent on the support of others for good and safe appointments
  - Familiarity
  - Both the pwld and supporters need to be informed about diabetes

Log

- 29/02: Checked and edited instances from node pwld should be the focus of appointments. Put this and the node independence and choice under heading the appointment is for the pwld.
- 03/03: Checked and edited instances from the node pwld should have independence and choice.
- 02/03: Updated node pwld should have independence and choice based on writing. Split into sub nodes of good support involves promoting independence and choice, appointment systems and professionals should promote independence and choice and promoting independence and choice is risky.
- 08/08: Added support contributions from ID interviews.
- 06/03: Added node pwld should be involved and proactive.
- 06/03: Considered node pwld are the same as others. Only rarely used so made subnode of pwld as different from others.
- 07/03: Went through instances of the repertoire pwld are dependent on the support of others. Went through node both pwld and supporters need to be informed. This may come under wider repertoires on the purpose of appointments.
- 08/03: Moved pwld should be involved and proactive to be a subnode of the appointment is for the pwld.
Appendix 21 - Reflexive Analysis

As recommended by Gough and Madill (2012) I have reflected on how my research interests, experiences, preferences and biases influenced my thesis including choice of topic, research questions, chosen methodological approach, interviews, analysis of data and interpretation of results.

My personal, academic and work experiences relating to diabetes and learning disabilities strongly influenced my choice of topic. My background in relation to diabetes is that numerous family members and several friends have Type 1 diabetes and I grew up in a household in which I was the only member who did not have diabetes. Additionally, members of my immediate family now live with debilitating complications of long-term diabetes. Discussions about all aspects of living with Type 1 diabetes have thus always been a regular part of my daily life. Although I do not consider myself to be a carer, I do sometimes provide support relating to diabetes and complications of diabetes to family members. This has included emotional support, help with hypoglycaemia, and during emergencies, occasional support with the tasks of daily living and attendance of healthcare appointments. I have also supported one family member to attend the structured education programme for Type 1 diabetes known as DAFNE (Dose Adjustment for Normal Eating).

My experiences with people with learning disabilities include personal friendship with someone with mild learning disabilities, a period of voluntary work experience as a tutor teaching online skills to adults with mild learning disability, attendance at the social history of learning disability group conferences and conducting interviews with adults with mild-to-moderate learning disabilities during my Master’s dissertation project. I also completed a health and social care module during my Psychology degree which included a strong focus on the lives of people with learning disabilities. I spent three years working as an administrator for a learning disability research group, where I was surrounded by research and discussions on a range of topics relevant to the lives of adults with learning disabilities, including healthcare.

My choice of methodological perspective and epistemological standpoint were influenced by several experiences. My undergraduate psychology degree included a module on critical social psychology and I made use of discourse analysis to complete the project for this module. This interest was furthered when I completed my Master’s dissertation, supervised by lecturers with an interest in critical social psychology and experience of methodology informed by the turn to talk.

The interview process was influenced by my experience. When interviewing participants with type 2 diabetes it was necessary to put aside my knowledge/assumptions based on my experiences of type 1 diabetes which were not always correct when considering type 2 diabetes. For all the interviews it was necessary to avoid assumptions that I understood terms/experiences and to ask people to explain from their own perspective. It is possible that I followed up more on responses that related to issues of diabetes management that I was familiar with. Knowledge of the literature, informal discussions, my expectations about the roles of healthcare professionals and being surrounded by family discussions of encounters with healthcare professionals especially in the context of letting off steam following annual reviews with GPs, may have influenced my assumptions including that appointments would include negative experiences, although this was not always the case.
for my participants. On the other hand, my experience working in a healthcare setting, including researching the views and experiences of healthcare professionals and observing their work on a daily basis, led me to consider their perspectives and difficulties such as demands on their time. In my research diary I have noted that I empathised with participants both when frustrated at not being able to intervene (supporters and professionals) but also on the few occasions when people with learning disabilities described frustration with having control of aspects of their lives/diabetes care restricted (e.g. the sugar being hidden and food thrown away).

My experience of family members with diabetes may have led me to focus more on the perspective of supportive others. In particular, I noted in my research diary that I empathised with supporters’ frustrations at being unable to intervene with unhealthy behaviours, something I have experienced myself, and some expectations by others that I can/have some responsibility for ‘making’ people behave in ways that are perceived as healthy. On the other hand, my experiences with people with learning disabilities and academic world surrounding this may have led me to privilege the perspective of participants with learning disabilities. It may also have led me to make assumptions about what the interviews and analysis would show. During the analysis and interpretation of findings I may have noticed and paid more attention to issues that relate to my own interest in diabetes and the experiences of people I know with diabetes. To ameliorate this, I was mindful of this possibility during data analysis and interpretation. I have also grounded my findings in examples and discussed findings with my supervisors.