An exploration of nutrition information practice in people with Type 2 Diabetes Mellitus

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Abstract

People with type 2 diabetes mellitus (T2DM) need information about what to eat in order to be able to self-manage their diabetes and to prevent long term complications. Their information activities involve accessing information from a wide range of sources. While studies have explored nutrition information activities, few have identified the instinctive, embodied and hidden nature of everyday information practice. This study aims to investigate the nutrition information practices undertaken by people with T2DM, to identify information accessed and used, and its perceived value.

The study consisted of a systematic review which informed an empirical research study. The systematic review utilised a narrative approach to the analysis of the 28 included studies. The empirical research study involved 20 people, 19 with T2DM (and one partner without T2DM) who were recruited through diabetes support groups and the researcher's workplace. Practice theory underpinned a social constructionist qualitative methodological approach. The diary-interview method involved participants completing diaries to capture their nutrition information experiences followed by an in-depth interview, to further explore these experiences. Data were analysed using thematic analysis.

The systematic review identified that nutrition information practices were key to the self-management of people with T2DM. The complexity of nutrition information and the tacit nature of information practice made this worthy of further research. The empirical study identified that experiences of diagnosis affected the way that T2DM was integrated into everyday lives and impacted on participants' T2DM self-management. Participants developed personal embodied 'rules of thumb' towards the way they managed their diabetes and expressed feelings of guilt if they strayed from these. Beliefs, embodied knowledge and skills affected engagement with information sources such as food labels and peer support groups. Information practices were influenced by the degree to which diabetes was embodied and were interconnected with food-related practices.

The study highlighted that some information, for example designed to assist in self-management and making food provisioning decisions, is challenging for people with T2DM to use. Sharing of information with peers in a support group setting could be of value to people with T2DM. People living with T2DM need ongoing support and encouragement in developing information practices that assist with their self-management.

Patient-led dietetic consultations could be enhanced through the use of nutrition information diaries to help identify and develop embodied nutrition information practices. Peer support groups could be recommended to help people who are newly diagnosed to come to terms with diabetes and to encourage diabetes self-management. The content and format of food labels is in need of review to enable interpretation by those with T2DM and to support the choice of foods with inherent nutritional value. This study challenges the current body of research relating to information activity and proposes information practice as a theoretical framework that could be used by practitioners and academics to explore information activities further.

1 Chapter 1: Introduction

1.1 Type 2 Diabetes Mellitus

Type 2 diabetes mellitus (T2DM) is an increasingly common chronic progressive disease (NICE, 2015). In the UK one in ten people over the age of 40 have T2DM amounting to approximately 3.4 million of the population who are living with the condition (Diabetes UK, 2019). Globally the prevalence of diabetes overall has increased from 4.7% of the world's population in 1980 to 8.5% in 2014 which is around one in eleven people (WHO, 2016, p. 6). The development of T2DM is mainly attributed to the preventable factors of increasing body weight and lower levels of physical activity (WHO, 2013, 2014). However, other risk factors include co-morbidities such as hypertension and those that are not preventable such as increasing age, ethnicity and genetics. People of South Asian, African-Caribbean or black African family origin are more likely to develop T2DM at a younger age and the risk of developing T2DM increases with the number of family members who have T2DM (NICE, 2018, p. 5).

Diabetes that is undetected or unmanaged will lead to a high level of glucose in the blood. If the blood glucose is left at a high level this will lead to complications as the high blood glucose damages blood vessels. These complications include problems with the eyes (retinopathy), the feet due to poor blood circulation and nerve damage (neuropathy), and the kidneys (nephropathy) and can lead to blindness, amputations and the need for dialysis. People with diabetes are also at higher risk of developing heart disease and having strokes. An essential aspect of diabetes management is the close monitoring of blood glucose levels and HbA1c results (a test which indicates blood glucose levels over the previous few months¹). Regular checks for vascular and nerve damage including eye checks for retinopathy, foot checks for damage to the feet and for the presence of neuropathy, kidney checks for the presence of nephropathy, and blood pressure and blood lipid levels are also needed. Development of complications of T2DM can be prevented by making sure that blood glucose levels are kept to near normal levels. Consuming a healthy diet and increasing physical activity levels can help in this process (Diabetes UK Nutrition Working Group, 2018).

¹ Diabetes UK define HbA1c as 'your average blood glucose (sugar) levels for the last two to three months'. (https://www.diabetes.org.uk/guide-to-diabetes/managing-your-diabetes/hba1c)

1.2 Nutritional management of T2DM

Nutritional management is a key component of T2DM self-management in keeping healthy and preventing complications, with a focus on delivery using a person-centred approach involving advice and guidance that is tailored around what people normally eat (Diabetes UK Nutrition Working Group, 2018) and the encouragement of family and carer involvement (NICE, 2015).

The Diabetes UK Nutrition Working Group (2018) have published nutrition guidelines for the prevention and management of diabetes. The focus of the advice in order to manage blood glucose levels is on weight management, aiming to lose weight and to increase activity levels. People with T2DM are advised to be aware of how much carbohydrate they are eating as foods containing carbohydrate impact on blood glucose levels; when foods containing carbohydrate are eaten they are advised to consume those of a low glycaemic index as these lead to a smaller rise in blood glucose levels. There are a range of dietary approches that have been found to help with the management of blood glucose levels as well as the prevention of cardiovascular disease in people with T2DM. These include the Mediterranean diet, the DASH diet and the low fat and low carbohydrate diet. However, further general guidance given by the Diabetes UK Nutrition Working Group (2018) includes the recommendation to: reduce salt intake; eat two portions of oily fish per week; eat more wholegrains, fruit and vgetables, fish, nuts and legumes; eat less red and processed meat; replace saturated fats with unsaturated fats; reduce consumption of refined carbohydrates and sugar-sweetened beverages; and limit alcohol to 14 units per week.

These guidelines are wide ranging with many concepts which people need to adapt and apply to their own lifesyle. Bodenheimer, Lorig, Holman, and Grumbach (2002) explain that self-management for people with long term conditions such as diabetes is 'inescapable' and state that 'each day, patients decide what they are going to eat, whether they will exercise, and to what extent they will consume prescribed medications'. Therefore a key part of the management of T2DM is the delivery of advice and information on how to live with diabetes and how to self-manage the condition (Ahmad, Ellins, Krelle, & Lawrie, 2014; Godbold, 2013). Information about nutrition and diet is known to come from a wide range of sources including HCPs, but also food labels, books, leaflets, social networks, broadcast media and the internet (Worsley & Lea, 2003). Therefore, as people with T2DM need to consider a wide range of dietary aspects in order to be able to make decisions about what to eat and to self-manage their condition they will need to access these different sources (Lloyd, Bonner, & Dawson-Rose, 2014; Longo et al., 2010). Although the provision of information itself does not lead to behaviour change (Coulter & Ellins, 2006) information is framed as a 'foundational

element' (Greyson & Johnson, 2016 page 2839) in behaviour change models where the provision of information leads to increased knowledge, confidence and motivation to undertake a change in behaviour.

1.3 Nutrition information services and sources of information for people with T2DM

The emphasis on the provision of nutritional information to people with T2DM by the Diabetes UK Nutrition Working Group (2018 p. 15) and NICE (2015 section 1.2) is through the referral to structured education. These programmes are designed to specifically meet standards for structured education (Diabetes UK Nutrition Working Group, 2018 p. 8; QISMET, 2010). Other services available to people with T2DM are informal support, defined by Diabetes UK (no date-a) as group based, peer led and technology sources and services provided by HCPs including dietitians.

Structured education

The Diabetes UK Nutrition Working Group (2018 p. 14) recommend that people with diabetes on diagnosis should be offered structured diabetes education and that those that already have T2DM should receive an annual follow up. However, the National Diabetes Audit (2020) suggests that there is poor uptake of the referrals for those who are newly diagnosed with diabetes. Receipt of an annual follow up to structured diabetes education is not audited. The key aspect to the effectiveness of structured education in the management of people with T2DM is the use of underpinning psychological theories to inform the delivery of the sessions (Skinner, Cradock, Arundel, & Graham, 2003). These theories focus on the facilitation of engagement with the information available during the sessions, however there is still a need to ensure that the information itself meets the needs of people with T2DM. The current programmes available to people with T2DM within the NHS that have been shown to be effective include DESMOND (Chatterjee, Davies, Stribling, Farooqi, & Khunti, 2018; Gillett et al., 2010), and X-PERT (Deakin, Cade, Williams, & Greenwood, 2006). Although the research evidence suggests that these programmes are effective there is limited evidence regarding their commissioning and availability across the country (Taylor & Bury, 2007).

Attending structured education may be a limiting factor in people with T2DM being able to access the nutrition information they need. The National Diabetes Audit (2020) found in 2019-20, while 77.5% of people with T2DM were offered structured education in their first year of diagnosis, just 13.3% attended structured education in that first year. Although this is an increase from the National Diabetes Audit in 2009-10 where 7.6% of people with newly diagnosed T2DM were offered

structured education and 2% of these attended sessions (Health and Social Care Information Centre, 2014) the figures still suggest that most people do not access structured education. Diabetes UK (2016) has proposed reasons for the low levels of attendance and suggest that attention should be paid to the way that the option to attend is made when the patient is offered a referral. They comment that with insufficient encouragement to attend and the use of the term 'structured education' having a 'negative association' with school, coupled with long waiting times to attend a session may have an impact. However the systematic review undertaken by Horigan, Davies, Findlay-White, Chaney, and Coates (2017) suggests that the reasons for individuals not attending structured education include logistical reasons and/or the perception that there would be no benefit. The study found reasons more wide-ranging that they had expected, and they propose that more creative ways of delivering structured education should be found.

Informal support

Wenzel (2016) in the review commissioned by Diabetes UK (no date-a) defines informal support as that which is less formal than structured education. The support may be available to people with T2DM through a wide variety of formats but is broadly grouped into three areas: group talks that may be led by HCPs or by lay people (e.g. cooking workshops, opportunistic sessions as part of other healthcare activities); peer² support groups (people with T2DM supporting each other e.g. face to face, telephone, online); and technologically assisted approaches such as online interactive websites for example websites which have interactive aspects to them such as HeLP-Diabetes (Ross, 2016). There is limited research evidence of the impact on self-management of informal support. However, Wenzel (2016) found that as informal support opportunities such as group talks or support groups may be led by lay people, participants many not have access to all the information that they need in order to self-manage, than that which would be available in a structured education programme.

Peer support group sessions have shown some improvement in diabetes self-management outcome measures. These include an improvement in blood pressure (Simmons et al., 2015) and reduced inpatient care utilisation (Yu et al., 2018) and thus may be cost saving (Wingate, Graffy, Holman, & Simmons, 2017). However, their main value appears to be the opportunity to talk to other people with T2DM, to share their experiences and to 'normalise diabetes' (Wenzel, 2016 p. 19).

Online interactive websites and programmes have been developed in order to meet the needs of people with T2DM to enable them to learn about how to self-manage in a flexible and informal way.

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² I use the term peer across the thesis to mean other people with T2DM and/or their carers.

These may be especially valuable to those who wish to find out about self-management in their own time, who may not wish to seek the advice of an HCP or who did not find structured education to meet their individual needs (Desmond, 2019; Ross, 2016). However, while these sources are accessible, people need the equipment, skills, and environment in order to make the most of online sources of information and advice.

Advice from health care professionals

Diabetes UK (no date-a) emphasises the value of HCPs in the provision of general information on living with T2DM and the importance for people with T2DM to ask to be referred to a dietitian (Diabetes UK, no date-c). The Diabetes UK Nutrition Working Group (2018 page 14) recommends that people with diabetes should be offered 'on-going nutritional advice guided by a registered dietitian' while NICE (2015) emphasises the importance of the provision of nutritional information from an HCP trained in nutrition (ibid 1.2).

Dietitians are the only health care professionals who are specifically trained and regulated by law to deliver nutritional information (BDA, 2020). There is evidence that dietetic advice is effective in supporting people with T2DM to self-manage (Agee, Gates, & Irwin, 2018; Siopis, Colagiuri, & Allman-Farinelli, 2021), although patients may not always find that dietetic consultations meet their needs (Ball et al., 2016). There are not enough dietitians to see all individuals who need nutritional advice (Nelson et al., 2000) and so people with T2DM may seek advice and guidance on what to eat from elsewhere.

The NHS expects all HCPs to support patients to self-manage (DoH., 2013; NHS Future Forum, 2012). As every HCP will come into contact with people with T2DM in their work (Diabetes UK., 2014) it is likely that there may be a greater involvement in the provision of care by HCPs not specifically trained in nutrition and diabetes. The provision of nutritional advice is considered to be part of the role of GPs and nurses in primary care (Leach & Shepherd, 2013; McClinchy, Dickinson, Barron, & Thomas, 2011; Moore & Adamson, 2002) and has been found to be effective as part of a multidisciplinary approach in supporting the management of people with T2DM (Ball, Hughes, Desbrow, & Leveritt, 2012; Renders et al., 2001). However, there is evidence which suggests that GPs and nurses in primary care may not have had sufficient undergraduate education in nutrition (DiMaria-Ghalili et al., 2014; Macaninch et al., 2020) and lack skills, knowledge and have limited access to evidence-based materials (Carney, Stein, & Quinlan, 2013; Diabetes UK., 2014; McClinchy et al., 2011). This affects their ability to deliver high quality/evidence-based nutritional advice.

HCPs are a key component in the delivery of patient-centred nutritional advice; however, the availability of patient-centred nutritional advice may be limited by lack of availability of HCPs who are trained in this area (dietitians) and the lack of training and skills in those who are readily accessible by people with T2DM.

Sources of information which are used by people with T2DM

Research exploring information seeking and information needs of people with T2DM has identified a wide range of sources that are searched for and used in order to help people with T2DM to self-manage (Biernatzki et al., 2018; Kalantzi, Kostagiolas, Kechagias, Niakas, & Makrilakis, 2015; Kuske et al., 2017; Longo et al., 2010; Meyfroidt et al., 2013). Kuske et al. (2017) undertook a systematic review into the information seeking behaviour of people with T2DM and identified the wide range of sources and processes that people with T2DM access and use. Similarly, Kalantzi et al. (2015) explored the information seeking behaviours of 203 people with diabetes (84.7% n=172 T2DM) attending a university hospital in Greece identified the wide range of sources used. While Longo et al. (2010) undertook a qualitative study exploring the way that people with diabetes (n=45 of whom 34 had T2DM) sought and used information. They described how their participants made use of the information explaining that 'patients actively weave their own information web'. Although structured education is promoted as a key component of diabetes management, Kuske et al. (2017) found just two studies exploring information with people with T2DM referred to groups as being a source of information.

The most common sources of information have been found to be GPs and the internet. While research suggests GPs are more trusted overall, the internet tends to be accessed by younger more highly educated people with T2DM (Kalantzi et al., 2015; Meyfroidt et al., 2013). For example Meyfroidt et al. (2013) in their qualitative study exploring nutrition information behaviour of 21 people with 'poorly controlled' T2DM over 60 years of age living in Brussels also found that GPs were the preferred source of information. The participants in the study undertaken by Longo et al. (2010) mentioned HCPs more frequently than other sources of information, using them to refute guidance from other information sources such as the internet. This was in contrast to guidance from friends and family with experience of diabetes who were seen to give participants 'first-hand' knowledge (p. 338).

Dietitians, however, are referred to less frequently as sources of information for people with T2DM and there is less research that focuses on nutrition information than diabetes information overall

(Kalantzi et al., 2015; Longo et al., 2010). Some research suggests that diet was the main topic about which people with diabetes were concerned (Broekhuis, van Velsen, De Franco, Pease, & Hermens, 2020; Kalantzi et al., 2015). However, Kuske et al. (2017) found that of 18 studies that explored information seeking in people with T2DM, just five found that information about diet was a topic that was searched for. While the systematic review undertaken by Biernatzki et al. (2018) into the information needs of people with diabetes suggesting that there has been less research in the area of diabetes than other diseases such as cancer did find that diet was one of the main topics of need for people with diabetes. They found that the main topic that people with diabetes needed was that relating to treatment and that of the 26 studies included, 11 identified nutrition as being an information need.

Information experiences

Duman, Farrington, Kerr, and Naish (2015) undertook a study of the data collected by ComRes (2015) through online interviews with people who had long-term conditions. The study found that 36% of 1567 participants disagreed with the statement 'when I was first diagnosed, I was given helpful information about my condition'. McDonald (2014) suggests that although 40% of people with long-term conditions were given information about their condition in the form of leaflets or websites, over half were not offered any information. For people with T2DM specifically, research suggests the availability and effectiveness of information support and education is variable. For example St. Jean (2012) found that their participants did not receive information in a timely way. Research suggests that those with medical conditions that respond to nutritional change may not receive the nutrition information that they need (McClinchy et al., 2011), indeed Meyfroidt et al. (2013) found that people with T2DM were not aware of the nutrition information that was available.

Research has found that there is an increasing amount of poor quality information online for people with T2DM (Weymann, Harter, & Dirmaier, 2015). This causes problems for patients as they may find it difficult to understand the information they obtain and may identify information that is not helpful to them and may do harm (Johnson & Case, 2012, pp. 18-21). Media is also a source of information for people with T2DM (Kuske et al., 2017), however, it is often a source of inaccurate information (Cooper, Lee, Goldacre, & Sanders, 2012). Jensen, Krakow, John, and Liu (2013) suggest that this may be because streamlining research evidence in order to bring out the 'story' has the potential to result in less clear messages. Although the media has a key role to play in the communication of food related messages (EFSA, 2012), the nutrition information in a food related message is likely to be ignored if the food promoted is not appealing or does not match cultural preferences (O'Key & Hugh-Jones, 2010). There is also research which suggests that the way some diseases are portrayed in the

media can lead to stigmatisation e.g. MacLean et al. (2009) in the case of obesity, which may limit the impact of general healthy-eating health promotion messages (McClinchy, Dickinson, Barron, & Thomas, 2013) and can lead to mistrust in the diet and health information found in the media (Lupton & Chapman, 1995).

Information about T2DM and about diet come from a wide range of sources. While GPs are considered the most trusted sources the internet is accessed most widely especially by younger people with diabetes. Research suggests that people with T2DM may not be receiving the information that they need in a timely way and are accessing additional information online and in the media. However, these sources may not be providing them with high-quality information about diet.

1.4 The study of information activities

Information is a basic human need (Ford, 2015, p. 1) and is defined as data which has become meaningful to the person using it (Case & Given, 2016, p. 6). Accessing and using information which 'brings about a change in [someone's] take on the world' (Case & Given, 2016, p. 6) is an everyday instinctive activity (Spink & Cole, 2006, p. 9). The provision of information is considered a treatment in its own right (Duman et al., 2015, p. 13; Patient Information Forum., 2013) and is embedded in the NHS constitution (DoH., 2013).

Information behaviour is an activity that people take for granted (Spink, 2010, pp. xi-xiii). Spink suggests that as the human brain evolved (ibid pp. 27-28), with enhanced working memory, information behaviour became part of 'human nature' (p. 26) and a 'core human capacity' (p. xii). While humans were beginning to learn about the best plants to eat, language skills were developing and foraging for food was becoming a 'survival' imperative (p. 50). Spink (2010) gives us the example of paleo humans and their use of cave paintings to show the best place to find food. She explains that, while there has been a focus on the channels and artefacts used in information activities, there has been less investigation into the way that these activities have been developed and suggests we need a greater understanding of how this innate ability works.

Information researchers when studying how people interact with information use the terminologies of information behaviour or information practice in order to explain the way that people access and use information. The majority of research studying information activities has been undertaken within the discipline of information behaviour (Soheili, Khasseh, & Mousavi-Chelak, 2017)

originating from a psychological viewpoint with an emphasis on the visibility of the process (McKenzie, 2003). However, information practice is an emerging approach to studying information activities enabling an exploration of practices that are hidden and influenced by the context within which they are undertaken (Lloyd, 2010; McKenzie, 2003; Savolainen, 2008). In this current study the term information activity is used when the concept could refer to either information behaviour or information practice. The individual terminologies of information behaviour or information practice are referred to depending on the discipline of the researcher.

Information behaviour

In order to further the understanding of how people access and use information, and to help explain this complex process, researchers have developed a number of models and theories (Case & Given, 2016, p. 144; Ford, 2015, p. 141; Johnson & Case, 2012, p. 104). For example Wilson's model of information behaviour (1996) (cited in Wilson, 1997), the Longo Health Information Model (Longo, 2005); the sense-making theory and practice model (Dervin, 1998); health information seeking behaviour (Johnson & Case, 2012). These models have been used to inform a range of studies investigating information behaviour in people with diabetes. Key findings from these studies were the active and passive aspect of information behaviour, the impact of demographics, the diagnosis itself, the timeliness of information and the length of time since diagnosis on information behaviour and the type of information needed.

Research has found relationships with active and passive information behaviour. For example Zare-Farashbandi, Lalazaryan, Rahimi, and Hasssanzadeh (2016) who undertook a survey of 362 randomly selected people with diabetes (T1DM, T2DM, diabetes during pregnancy and prediabetes (specific numbers are not reported)) in Isfahan. They found an increase in active information seeking in those with diabetes during pregnancy and those that had a family history of diabetes. They also found that the stage of the diabetes diagnosis impacted on the information behaviour finding that with an increase in the length of time since diagnosis there was an increase in the passive information receipt. However Meyfroidt et al. (2013) identified the passive nature of information behaviour on T2DM diagnosis. Although this is in contrast to the impact of other diagnoses on information behaviour. For example Johnson and Case (2012, p. 55) refer to 'frantic' searches for information in the early stages of a cancer diagnosis.

Longo et al. (2010) found that the modality of the information influenced information behaviour. They identified how people with diabetes may passively and actively receive information from

sources such as healthcare, family and friends and the media. Meyfroidt et al. (2013) identified the passive receipt of information from healthcare professionals while Longo et al. (2010) found that passive information behaviour was a 'by-product' of everyday activities such as watching television. However, Kuske et al. (2017) found that there has been a shift to more active information seeking behaviour with the increased availability of information on the internet.

Broekhuis et al. (2020) in their study of information behaviour in everyday life identified avoidant information behaviour along with active and passive information behaviour describing passive as 'fortuitous' information seeking. Rather than the behaviour being related to source or context, they identified the way that everyday activities impacted on information behaviour. Their study utilised a 28-day electronic diary of information to record information behaviour situations followed by a debriefing interview with 12 people with T2DM aged 40 to 70 years old. They found that food and nutrition were the most common aspects that influenced information behaviour and notably found that there were many more passive health information behaviours than active or avoidant. The passive contexts occurred across a range of life activities, examples include the spontaneous discussions about food and nutrition that can arise with family and friends and the identification of an interesting article while browsing online on their mobile phone. Active contexts included cooking dinner (n=12 incidents) where a common action was to check nutrition information online. Avoidant contexts included not having enough time to think about health or not having any current issues of concern. These avoidant behaviours are in contrast to those identified by Johnson and Case (2012, p. 152) who use the term avoidance behaviour as a specific behaviour impacted on by context, for example beliefs about a disease (e.g. family experiences) preventing engagement with information.

While studies have explored active and passive information behaviour, others have found that people with T2DM may not be aware of the information that they need. For example St. Jean (2012) developed and used a card-sorting technique to identify the potential changes in information needed over time with 34 people with T2DM. The study identified that people with T2DM may not be aware of information that they need. St. Jean (2012) termed this 'incognizance' (p. 156) explaining that the timeliness of information is a key factor in being able to self-manage T2DM.

Kuske et al. (2017) and Kalantzi et al. (2015) found that social demographic aspects of the participants and length of time since diagnosis impacted on the information seeking behaviours and preferences. For example Kalantzi et al. (2015) found that older people felt that they were less in need of information and Kuske et al. (2017) found that older people are more likely to need information provided verbally. Kalantzi et al. (2015) found that having diabetes for longer meant that

their participants felt they had sufficient information and similarly as explained above Zare-Farashbandi et al. (2016) found with the increased length of time since diagnosis participants were less likely to search for information. While St. Jean (2012) identified that although information needs do change over the course of the disease that this is individual and that people with T2DM may not be aware of their information needs.

Information Practice

The term information practice is introduced as a concept to describe the processes of needing, accessing and using (or not using) information because of the 'social and cultural factors' that influence information activities (Ford, 2015, p. 34). Researchers using the terminology information practice include for example Savolainen (2008), McKenzie (2003) and Lloyd et al. (2014). The commonality between them is the emphasis on the social aspects of information practices being part of everyday lives as opposed to the cognitive psychological approach of information behaviour meeting an individual's needs and goals. There is limited research in the area of information practices with people with T2DM and none of the studies explored here refer to the information practices of people with T2DM. However the studies undertaken by Lloyd et al. (2014) and McKenzie (2003) involve health related conditions. Lloyd et al. (2014) explores the practice with people with long-term life-threatening conditions and McKenzie (2003) with women pregnant with twins. The analysis of these studies begins with Savolainen (2008) whose work on everyday information practice started with a study in 1995 with teachers and workers which identified that information seeking was part of everyday life practices (Savolainen, 1995) and was developed in 2008 into the model for everyday information practice (Savolainen, 2008).

Savolainen (2008), in developing the model for everyday information practice, drew on the ideas of social phenomenology and practice theory. Referring to everyday life and practice, he explains that the main components of information practice are 'information seeking, information use and information sharing' and so information practice is defined as the ways in which people seek, use, and share information (p. 50). Information practice is used as opposed to information behaviour as this brings the activity into the everyday. He notes that much information is social, for example much of the information accessed is through social activities such as watching television, reading newspapers, using email, Twitter and Facebook. Savolainen (2008) is more concerned with the 'social constructivist' viewpoint, describing information practice as a set of socially and culturally established and habitual ways to identify, seek, use and share the information available in various

sources such as television, newspapers and the internet. He explains that information practice 'sits within the broader concept of everyday practices and projects' (p. 4).

Savolainen (2008) applied the model to an empirical study with a convenience sample of environmental activists (n=20) and unemployed people (n=18) using a qualitative approach of interviews and source mapping. Both groups favoured printed broadcast media and networking as part of their information practice. He noted the habitualisation (p. 112) of the activities and the difficulties participants had in recalling the specifics of their everyday (i.e. habitual and hidden) information practices. However, when the study explored 'problem specific information practices', human, networked and organisational sources were preferred (p. 141); and for health related information practices, these would begin with directly accessing a doctor if the information was urgent or the internet if not. Indeed health issues were one of the main 'triggers' to 'processes of problem-specific information in everyday contexts' (p. 142). Information practices depended upon embodied knowledge and were habitual (pp. 202-203).

McKenzie (2003) explains that the models of information behaviour such as Wilson 1996 (Wilson, 1997) focus on active goal-related aspects of information behaviour and do not take into account the holistic everyday aspects of people's lives. Her research involved the use of a social constructivist approach to the oral collection of diary data twice in one week from 19 Canadian women pregnant with twins followed by semi-structured interviews. The study identified a range of practices including, for example, 'active, incidental and serendipitous' practices that were often impacted by incidents of daily life. From this McKenzie (2003) developed the 'two-dimensional model' of information practices. The model identifies the modes of information seeking (active seeking, active scanning, non-directive monitoring and by proxy) against the practices of connecting and interacting. While McKenzie (2003) explains that these findings relate to the physical characteristics and social meanings of the participants, further work could be undertaken to explore the impact of social contexts on information practices.

Lloyd et al. (2014) explain that the ability to interact with information will vary according to the skills and knowledge held about a particular health condition. They define health information practice as the way 'patients use information to situate themselves and to inform their decision making in relation to the day-to-day management of their chronic illness'. The study involved interviews with people who had the life-threatening and complex condition of human immunodeficiency virus (HIV) (n=10) and chronic kidney disease (CKD) (n=8) and explored information practices and skills in managing these. They use the term 'information modalities' to group together information sources

that formed the participants' 'information landscape' as a way of explaining the space that is 'textual space, social space, physical space' that each source inhabited. For example, 'corporeal and embodied sources' were those that resulted from physical symptoms and feelings, while 'epistemic sources' were those that came from the guidance and advice from doctors about, for example, treatment regimens. 'Social sources' were those that came from experiences with others who had the same condition perhaps in the group setting. However, nurses were considered mediators to the advice from doctors and so are also included in the social sources information modality.

In the study participants used a range of information activities as part of the information practice. For example, these were orienting, that is activities that helped them to understand their condition, and information sharing in order to assist others to understand the condition. This could be with professionals such as nurses where they are explaining their condition and who 'act as a bridge' between patient and doctor, but this also could be with peers, in the form of their experiences or practical ways of coping with the condition. They also found that participants worked on creating their own information from the information they had collected, with one participant using the term 'kidney bible' to describe how they had kept information from a range of sources together in one place.

Lloyd et al. (2014) particularly note the wide range of sources of information and processing skills that participants used in order to engage with the information, not just the information from health professionals but also information from their own bodies (corporeal information) and from information that is shared between peers. They comment therefore that the 'information landscape' will change when a diagnosis is made and along the course of the condition as health literacy changes as an outcome of health information practice.

There is limited research with people with T2DM on the use of information practices to explore information activities. Two studies Savolainen (2008) and McKenzie (2003), have identified models relating to information practice. All studies in their justification for their approach refer to the psychological basis of information behaviour and the goal-driven approach as opposed to information being an everyday activity undertaken in a social setting. All studies referred to the wide range of sources and processes utilised in order to undertake information practices, however only Lloyd et al. (2014) refers to the use of embodied knowledge as an information source.

Discussion

In this section I have sought to explain the complexities of information activities and to justify the need for a model to be used to explore the information activities undertaken by people with T2DM. I have explained a range of models and theories that have been applied to people with T2DM and or to health-related scenarios. The overarching theme of all of the theories and models is the complexity of the activities, the wide range of sources that people use as part of their information activities, the increase in available information which emphasises the skills needed in being able to access and judge information and the active, passive and habitual nature of information activities. While there has been a challenge to the Savolainen (2008) model and whether it is indeed practice rather than behaviour (Wilson, 2009), the debate reaffirmed that information behaviour is set in the field of psychology and suggests an individualist approach to information activities. However, arguments set out in the debate suggest that as information practice was influenced by practice theory, the information practice model is set in the sociological discipline and thus suggests a sociological approach to further research as recommended by Lloyd et al. (2014) and McKenzie (2003). Additionally both Savolainen (2008) and Lloyd et al. (2014) highlight the hidden, tacit and skills based approach to information practice. In this final point the researcher is mindful of the following: Nettleton, Burrows, Malley, and Watt (2004) findings from their work exploring the use of the internet by families, that information is embedded in every day practices alongside other resources; and Spink and Cole (2006) identifying that information behaviour is an instinctive behaviour. The factors point towards the identification of information practice as a potential activity that may be useful in researching information activities.

Other researchers have also suggested that human behaviour may be more helpfully considered as practices. For example, Cohn (2014) has identified this in relation to health behaviours which he believes would be better viewed as health practices. His proposal is based on findings that individual behaviour change theories have had limited success when associated with changes related to eating (Delormier, Frohlich, & Potvin, 2009) as they under estimate how much eating is 'embedded' into everyday life (Delormier et al., 2009; Warde, 2005). For example, Halkier and Jensen (2011) in their study with Pakistani Danes found that the participants were knowledgeable about 'normative' healthy eating and spoke about it in terms of tacit, taken for granted knowledge. However, the incorporation of this knowledge into everyday eating varied according to the social environment where the incorporation of healthy eating was undertaken if it was practical to do so.

This section has explored the research relating to information activities and identified that information practice may be the most appropriate approach to explain information activities of

people with T2DM. Practice theory as the overarching framework within which information practice is situated is discussed and explained in the next section.

1.5 Practice theory

Practice theory is the theory of 'embodied, materially interwoven practices centrally organised around shared practical understandings' (Schatzki, 2001a, p. 12). Schatzki (2001b, p. 56) gives examples such as 'cooking practices, rearing practices, political practices, farming practices, negotiation practices, banking practices, and recreational practices'.

Practice theory has its beginnings embedded in philosophy (for example Wittgenstein), social theory (for example Bourdieu, Giddens) and cultural theory (Foucault) and as such is a broad concept with no 'unified practice approach' (Schatzki, 2001a, p. 11). While the concept has been criticised for this very point (see for example Schmidt, 2018), as identified above it has been useful to explain why behaviour change models have limited success with changes related to eating which is 'embedded' into 'everyday life' (Delormier et al., 2009) and to consumption as each practice is held in place by the next (Meier, Warde, & Holmes, 2018, p. 210) (that is other practices are holding in place the practice which the intervention is intending to change).

Schatzki (2001a, p. 17) suggests that part of the development of practice theory was the rejection of the 'Cartesian' view that mind and body are separate. So instead of referring to beliefs and desires (i.e. the mind), thoughts are seen together with behaviours. Practice theorists examine 'know-how, skills, tacit understanding and dispositions' (ibid, p. 17) and importantly those that are 'materially mediated' (p. 12).

Reckwitz (2002) explains that practice theory is a type of social or cultural theory. It is about the 'everyday' (mundane) and 'lifeworld' (p. 244) and about tacit, taken for granted behaviours where knowledge and understanding are implicit. These behaviours are sited in the body (i.e., in what people do) and in corporate artefacts (i.e., materials) such as the television or the house. He defines a practice as 'a routinised way in which bodies are moved, objects are handled, subjects are treated, things are described and the world is understood' (p. 250).

Shove, Pantzar, and Watson (2012) influenced by Reckwitz (2002) produced a rationalisation of the components on practices in order to be able to explain how practices develop, and how they are interwoven with other practices. They explore the changes in social life through the lens of social

practice and explain that practices are the connections between materials, competencies and meanings (aspirations). 'Practices are reproduced as provisionally recognizable entities' and 'a practice is a necessarily provisional but relatively consistent relatively enduring integration of elements' (p. 82). They explain that practices change as the 'ingredients' change giving the example (among many others) of the increasing incidence of obesity which has resulted in the practice of regular weight measurements by individuals (p. 110).

Warde (2013), whilst accepting that there is little agreement between practice theorists, explains that they all tend to emphasise doing (i.e. embodied knowledge) over thinking. That is, when the competence in being able to do something -'we just do it' (p. 18) is emphasised over the strategic decision making. 'Mutual intelligibility' as opposed to personal motivation, and the importance of using tools to help with decision making is emphasised. Warde (2013, p. 24) considers eating as a compound practice which he describes as being made up of four integrative practices: supplying of food, cooking, meal occasions, patterns and taste, which he then redefines as nutrition, cooking, etiquettes and gastronomy.

Southerton (2013) in his paper on habits, routines and consumption, similar to Shove et al. (2012) divides social practices into three aspects. Dispositions which are culturally derived, procedures which are based on tacit knowledge and embodied skills and sequences of performances (which he explains are the materials) of everyday practice. He emphasises this further by giving the example of a family eating together. The very process of eating together requires a great deal of co-ordination and time which he sees as a material.

Cohn (2013, pp. 75-81) explains that 'everyday practices are always composites of an infinite number of actions and activities' (p. 78), that 'eating is a bundle of activities' (p. 75) and is an embodied experience of food practice. He questions the idea that people think 'rationally' when making decisions about what to eat and that it is simplistic to see diet as something that an individual can have control over.

Twine (2015) uses the example of the rise of snacking in our everyday eating as a social practice. He explains that social practices develop as society changes. For example, with the increase in vending machines, the changes in the working day where breaks are no longer regulated and, for those working in the office environment, food is more commonly eaten at the desk, the social practice of snacking has developed.

In this section I have laid out key practice theorists who are relevant to the study of information practice with people with T2DM. Schatzki (2001a, p. 17), Reckwitz (2002) and Shove et al. (2012) are key influencers. Warde (2013), Southerton (2013), Cohn (2013, pp. 75-81) and Twine (2015) for their work on eating practices as there will be a link between nutrition information practices and food and eating practices. Whilst there is apparent agreement of the core components of materials, competencies and meanings only Shove et al. (2012) have been explicit in setting these down, however, there is apparent overlap in that practices are tacit and hidden. In the next section the researcher explains further the elements of practice theory.

The elements of practice theory

While the elements of practice theory consisting of materials, competencies and meanings are widely accepted, there is however no agreed 'typology' of these elements (Southerton, 2013), although Shove et al. (2012, p. 14) has given a simplified explanation of each element:

- Materials including things, technologies, tangible physical entities, and the stuff of which objects are made
- Competencies which encompass skill, know-how and techniques
- Meanings in which we include symbolic meanings, ideas and aspirations'

However, a further detailed understanding of what each element encompasses is needed in order to be able to apply the concept of information practice. While the categorisations of the material element of practice theory are generally accepted (see for example Twine, 2015) in information practice the material aspect is less tangible. It is the carrier of the information that is the material. In the same way as technology, e.g. the internet, is a mediator, something which makes the practice possible, the 'information modality', the information source, the information artefact which is the material. For Savolainen (2008) information sources used by the participants were broadcast media, social media and the internet, but also health care professionals. Byström and Pharo (2019, p. 105) explain that information artefacts include 'digitised, in print, as broadcasts, as databases, as registers, as persons, as signposts, as timetables, as social media platforms, as news, as laboratory tests, as records'. Lloyd et al. (2014) found that corporeal knowledge from an individual's body was a source of information (referred to below as corporeal information). However, also were social sources such as the shared information between peers and the advice and guidance given by health care professionals. They term the guidance from health care professionals 'epistemic information', that is, objective information that is tangible, 'rule driven' and can be written down.

Where competencies are concerned Twine (2015) includes knowledge as part of the typology, however, Southerton (2013) refers to tacit knowledge and embodied skills and Cohn (2013) refers to embodied knowledge. Although Lloyd et al. (2014) also uses the term embodied knowledge this refers to corporeal information, that is a source of information enacted through physical behaviours. However Lloyd et al. (2014) defines competencies from the view point of health literacy skills, as 'the ability to understand information that is being disseminated by medical, nursing or allied health professionals'.

Meaning encompasses the reason for the practice, the experience of the practice and the expected outcome of the practice. One aspect not included in Shove et al. (2012) is that of personality and preference, that is disposition for a particular practice. While Southerton (2013) proposes the concept of disposition as a driver for the practice, sitting outside practice elements, it may also be useful to incorporate into the typology under the heading of meaning, i.e. why a particular practice was selected and what were the aspirations of the practitioner for the outcome of the practice. Another expected outcome of practice or aspiration is that of the development of health literacy skills as explored by Lloyd et al. (2014). Participants undertook information practice to learn more about their condition and thus attained health literacy skills relating to their condition. In this way they developed skills which became competencies and were able to undertake further practices.

In the example given above, the meaning, that is the need to develop health literacy skills, drove the information practice of the participants in Lloyd et al. (2014), with the outcome being the development of skills. In this way competency enables different practices to be undertaken such as that of self-management. Indeed Shove et al. (2012, p. 32) explain that each element is 'mutually shaping'. As new elements arise or different combinations of the elements work together, new practices are formed. Each element will influence the information practice undertaken.

Researchers generally agree that the main elements of practice theory are materials, competencies and meanings, however there is not a generally agreed typology. While materials could have tangible components, they may also consist of resources that may not be tangible such as those resulting from communication between people for example from HCPs and from corporeal information. Competencies or know-how may include explicit knowledge but also include embodied knowledge that is assumed and tacit. Where meaning is concerned, whilst a practice can be driven by personality, i.e. disposition or preferences for undertaking a practice, the disposition may also give meaning to the practice, that is the outcome of the practice. The desired outcome of the practice, if

achieved, may also lead to a competency that is then applied to a new practice as in the example given by Lloyd et al. (2014), in the development of health literacy skills. From this short explanation additional typologies can be added to the elements set out by Shove et al. (2012, p. 14) (in italics bold):

- Materials including things, technologies, tangible physical entities, and the stuff of which
 objects are made, information artefacts (Byström & Pharo, 2019), epistemic information
 from HCPs, corporeal information, social sources (Lloyd et al., 2014)
- Competencies which encompass skill, know-how and techniques, embodied knowledge (Cohn, 2013)
- Meanings in which we include symbolic meanings, ideas and aspirations, dispositions and preferences (Southerton, 2013)

Practice theory research and the link with embodiment and everyday life

Practice theory has been used to study the impact of the development of progressive long-term conditions and ageing on the experiences of daily lives. For example, Bell, Tyrrell, and Phoenix (2017) in discovering that the development of Meniere's disease led to the need to develop new skills in day- to-day living, reviewed their data with 20 participants using practice theory as their theoretical framework. Practices were broken as a result of the disease and new practices and activities needed to be developed. This study highlighted the invisibility of daily practices, the fear that what is known about everyday life can no longer be relied on and the tiring nature of having to develop new practices as a result of the development of a long-term condition. Similarly, Cohen and Cribbs (2017) when exploring the food practices in 31 lesbian, gay, bisexual and transgender older adults (age range over 60 to over 90 years old) found that changes in older people's lives impacted on each of the practice theory elements. As life situations changed so did their practices and in order to be able to undertake these new practices, new materials (e.g. microwaves) new skills (e.g. competencies in cooking) and new meanings (e.g. maintaining health) were developed. The authors comment that interventions should 'account for the dynamics' in everyday food practices. However, Harries, Rettie, and Gabe (2019) when exploring the everyday management of a long-term condition in 25 young people with type 1 diabetes (T1DM) use the term 'interrupted' to explain the impact of chronic disease on social practices. In their example (with young people with T1DM) they identify the impact that the self-management aspects of having the disease can have on the practices of the social group, such as going for a walk or in making a choice from a menu when dining out, while a blood sugar measurement is taken. In order to incorporate this 'group' social practice a fourth element is

added to materials, competencies and meaning, that of 'social rules'. In the examples given the 'social rules' are interrupted and the authors propose that self-management activities would be more likely adhered to if the guidance on these activities took into account the social rules of daily lives and the integrated nature of practices. Lubi (2019) uses practice theory to explore the impact of information-seeking behaviour on enabling everyday practices in 16 people living with Parkinson's disease in Estonia. While Parkinson's disease was noted to change the practices that the participants undertook, participants needed to live their normal lives for as long as possible and this meant that they did not seek information on living with the disease in the late stages until the disease had progressed.

Researchers have explored the interrelated nature and connectivity of practices. For example Castelo, Schäfer, and Silva (2020) in their theoretical paper suggest that not only are food practices interconnected but that they may be part of a 'nexus' or network of practices. In this way a practice may be seen as one practice, for example snacking, as defined by Twine (2015) or seen as a 'bundle' (Cohn, 2013). Eating may be interconnected with a larger group of food practices such as meal planning, shopping, cooking, serving, but also linked as part of a network with other practices such as socialising, leisure, mobility, working. Warde (2005) describes such practices as being interconnected and so are seen as 'integrative', that is grouped together with each individual practice depending on another as in the case of shopping. He also uses the term 'dispersed' to relate to practices which are often part of integrative practices and gives the example of consumption which is often undertaken without thinking. While Hennell, Piacentini, and Limmer (2020), in their study with three mixedgender friendship groups aged 18 to 22, suggest that drinking practices amongst young people should be seen as a bundle, with each 'interconnected sequential' practice ('Planning, Getting Ready, Pre-drinking, 'Going-Out', Getting Home, Story-telling') being dependent upon the next. However Wills, Meah, Dickinson, and Short (2013) identified that practices, particularly those undertaken in one setting such as the kitchen, are more than intertwined or interconnected, they are entangled and it is impossible to see where one practice ends and another begins.

One of the reasons practices can be difficult to understand is because they become embodied throughout the life course (Wallenborn & Wilhite, 2014). Embodiment refers to the way that people think about themselves (Merleau-Ponty, 1962) and is an intertwining of the mind and body leading to the formation of an identity (Crossley, 1995). The process is influenced by individual experiences that develop over time (Merleau-Ponty, 1962) and impacts on the way that people with T2DM see themselves and how their identity as a person with a chronic condition develops.

Activities undertaken by people with long term conditions when they are 'looking after themselves' (Charmaz, 1993, pp. 134-166) can be seen as embodied practices. Research suggests that embodied practices become more firmly shaped when there is an acceptance and so become a *normalised* part of everyday life. For example Funa (2012) in her study of Black men with type 2 diabetes in America found that acceptance of the disease was needed in order for participants to be motivated to self-manage and Whittemore, Chase, Mandle, and Roy (2002) found that once women with T2DM had integrated their diabetes they were able to manage their diabetes 'simply and efficiently'. St. Jean (2012) found that self-management was assisted by having an embodied disposition that valued information activities. Embodiment itself can impact on the process for acceptance and coming to terms with a condition. Engman (2019), in her work with post-operative organ transplant recipients, found that the impact of the transplant was related to how far certain behaviours had been embodied. For example, children, as they were still developing, found coming to terms with the transplant easier than young adults who had already developed autonomous behaviours that shaped the way that they lived their lives.

Self-management practices become embodied over time. They incorporate decisions and practices that are made and undertaken automatically, without thinking. They are based on assumed, implicit, tacit and embodied knowledge. However, the process of embodiment is dynamic and evolves over time. Once self-management practices are developed embodiment becomes stable and fixed. People will not be aware that they are undertaking these practices and as the knowledge on which these practices are based becomes embodied, they will no longer be aware of the information underpinning these practices. Researchers suggest therefore that interventions should focus on changing practices rather than individual behaviour (Meier et al., 2018). Indeed van Kesteren and Evans (2020) note that cooking practices are often hidden and tacit and that knowing how to cook is embodied and difficult to 'articulate' (p. 5). In order to study the social practices of cooking with 25 mothers with young children from different areas of Bristol, the researchers utilised a 5-day cooking diary which they used as prompts during the qualitative interviews. They found that while the mothers were knowledgeable about what was healthy food, they did not incorporate the knowledge into their cooking practices and concluded that giving information without understanding food practices will have little impact.

Researchers have used the term 'rules of thumb' or heuristics to refer to patient self-management decisions and practices that do not have a clear origin or evidence base (Swindell, McGuire, & Halpern, 2010). For example the food practices informed by the embodied knowledge in the study referred to above by van Kesteren and Evans (2020) and the everyday activities undertaken by

people with long term conditions when they are 'looking after themselves' as described by Charmaz (1993, pp. 134-166) are guided by 'rules of thumb'. 'Rules of thumb' are unspoken assumed, taken for granted decisions where the history or reason for the action or decision is not clear.

Practice theory has been used to explore the impact of chronic disease on everyday social practices. While the three elements of meaning, competency and materiality have commonly been used, some studies have also used a fourth element that of social rules. The progressive impact of a long-term condition has been seen to interrupt and to change everyday practices and new practices are developed in order to respond to the changing nature of the disease. Studies having found that practices are embodied, interrelated and entangled with each practice holding another in place, propose that the delivery of interventions needs to focus on the practices in an holistic way, rather than focusing on individual behaviours.

Practices such as everyday self-care activities undertaken by those with a long-term condition have become embodied through a process of coming to terms with the condition. The degree of embodiment and the way that practices are embodied impacts on the ability to self-manage,. self-management embodied practices become ingrained with individuals using 'rules of thumb' based on tacit knowledge that develops over time.

1.6 Conclusion

The self-management of T2DM is complex, requiring an understanding of blood glucose levels, HbA1c, the complications that may occur and a wide range of nutritional concepts in order to be able to optimally self-manage the condition. Whilst research shows that structured education is the most effective method of helping people to be able to self-manage, only a small number of people with T2DM actually attend. While dietitians are the only people who are trained to give dietary advice they do not feature widely as nutrition information sources in information research relating to people with T2DM. Therefore, people with T2DM are reliant on information from other sources where there may be concerns about the quality of the information. There is a paucity of research relating to the information activities of people with T2DM, however the research that has been undertaken utilises different models. As information activities are instinctive this suggests an approach that is based on uncovering hidden and tacit behaviours as in practice theory, which has been used to research information practice. However there is not an agreed typology for the elements of practice theory and so the structure suggested by Shove et al. (2012, p. 14) with some additional components identified from research is given. Practice theory has been used as a

framework to explore the impact of long-term conditions. Everyday practices are changed as a result of the embodiment of a long term condition. Practices themselves are embodied, interrelated and entangled, however there is limited research relating to T2DM and practices.

1.7 Aims, objectives and research questions

Aim

This study aims to investigate the nutrition information practices undertaken by people with T2DM.

Objectives

- To identify the nutrition information that is used by people with T2DM in order to selfmanage their T2DM
- 2. To examine the types of information and their accessibility and usability for the participants in helping them to self-manage their T2DM
- To identify and describe the information practices (meanings, competencies and materials)
 undertaken by people with T2DM and what impacts on the development and enactment of
 these practices.

Research questions

- 1. What nutrition information do people with T2DM and their partners/carers need?
- 2. What nutrition information do people with T2DM and their partners/carers use?
- 3. What are their experiences of accessing and using the information?
- 4. What practices (meanings, competencies, materials) are they using in order to acquire and make use of the information in order to manage their T2DM?

1.8 Overview of the Thesis

The introductory chapter has set the scene for the study, by explaining the importance of self-management for people with T2DM and the central nature of information activities within self-management. Potential theoretical frameworks are reviewed, and practice theory is identified as the main theoretical framework used to underpin the study. Chapter two encapsulates the systematic review which forms the first part of the study and informs the empirical research study. Chapter three sets out the research design for the empirical research study. The ontological and epistemological approach and the process undertaken in the development of the method, data collection and analysis and ethical issues are described here. An overview of the participants and the personal context of T2DM and food practices is detailed in chapter four. Chapters five and six

present the main findings from the empirical research study. Chapter five explores the information practices relating to food labels and peer support groups. The experience when using food labels and the collaborative nature of peer support groups are identified. Chapter six explores the impact that embodied diabetes can have on information practices and the fundamental nature that information practice has in directing self-management and being able to self-manage. Chapter seven discusses the findings from the two studies, linking them with the research literature and identifying the significant and original contribution this study has made to what is known about nutrition information practices in people with T2DM. The chapter includes recommendations for practice and for research and finally concludes by summarising the key points learned from this study.

2 Chapter 2: Systematic narrative review

2.1 Introduction

The limited research base relating to nutrition information practices undertaken by people with T2DM indicated that a systematic review preceding the empirical research study would be beneficial to determine the current state of academic knowledge in regard to the study's research questions. The aim of the systematic review is to identify and critically review relevant research that could assist in identifying gaps in knowledge in regard to the study research questions and provide potential direction for the empirical research study. While studies indicate that diet is a key information topic for people with T2DM (Kuske et al., 2017), there is limited research specifically focussing on diet and information activities in people with T2DM.

The aim of a systematic review is to synthesise research relating to a specific research question. A structured and methodical approach is used to identify relevant studies through extensive searching, based on searches using inclusion and exclusion criteria, the application of critical appraisal, and the amalgamation of the findings from the included studies in order to answer a specific research question. By using a thorough and systematic approach to the identification of studies the process aims to avoid potential selective inclusion of studies that are of interest to the researcher (Greenhalgh, Thorne, & Malterud, 2018).

With little research in the area of interest of this current review, studies with heterogenous methodologies are likely to be identified (Denscombe, 2014, p. 135). Therefore, a narrative approach to summarising the findings of the systematic review was selected as this would enable the combining and reporting on the findings of studies from wide-ranging methodologies in order to present existing knowledge relating to the research question.

The aims of this systematic review are to identify the nutrition information activities (i.e. behaviours or practices) of people with type 2 diabetes. Specifically, their information needs, sources of information used, how this information is made use of, and their experiences in using this information.

The research questions for the systematic review are aligned to the overall research questions:

- What nutrition information do people with T2DM need and use in order to manage their T2DM?
- 2. What information activities (behaviours, practices, proactive, active, passive, avoidance behaviours) do people with T2DM use in order to acquire and make use of nutrition information in order to manage their T2DM?

These research questions were used to inform the search strategy and the study selection process.

2.2 Methods

The PRISMA checklist 2020 (appendix 5) (Page et al., 2021) was used to inform the process of the systematic review. The process for identification of studies followed the flow diagram (figure 1) as laid out in the reporting items for systematic reviews and meta-analyses (PRISMA) (Moher, Liberati, Tetzlaff, & Altman, 2009).

Search strategy

The systematic review utilised the following data bases as these were considered likely to include relevant studies: PubMed, CINAHL, PsycINFO, Google Scholar and Scopus. A full description and rationale are included in appendix 1.

A search within these databases was undertaken in July 2019 and updated in October 2020 and March 2021 utilising search terms informed by the study's research questions. The following search terms informed by the research literature and including MESH terms were identified as follows. The terms for type 2 diabetes were: "Type 2 Diabetes", Diabetes, Diabetic, "Type 2 diabetic". The terms for information activities were: "Information behaviour", "Health information behaviour", "Consumer information behaviour", "Human information behaviour", "Information practice", "Information work", "Information communication", "Information sharing", "Information seeking behaviour", "Health information seeking", "Information access", "Information need", "Information use", "Health information processing", Information, Passive, Active, Proactive, Avoidance. The terms for nutrition were: Diet, Dietary, Dietetic, Dietitian, Dietician, Nutrition, Nutritionist, "Nutritional therapist", Cook, Cooking, Cookery, Cookbook, Recipe, Food, Eat, Eating, Weight, Obesity, "Body mass index", BMI, "Healthy Living", Lifestyle. The full list of search terms is included in appendix 2.

Studies from the searches from the different databases were combined using a reference management software package (Endnote, Clarivate TM) and duplicates were removed.

Study selection process

The PRISMA 2009 flow diagram (Moher et al., 2009) was followed in the identification and selection process of the studies. Studies that did not meet the review criteria (informed by the study's research questions) were excluded at each stage of screening. Following screening of titles and abstracts against the review criteria, full text copies of the studies which met the review criteria were analysed for their referral to the nutrition information behaviour or practice of adults with type 2 diabetes. The studies which met the inclusion criteria were included for final analysis. The citations within these studies were screened against the review criteria and the forward citation facility in Google Scholar was used to identify potential further studies for inclusion in the review. The titles and abstracts of the studies identified from this process were screened against the review criteria and those that were included were then subjected to full text screening before finally including relevant studies in the review.

Inclusion and exclusion criteria

The inclusion and exclusion criteria were informed by the study's research questions. Studies were included if they were empirical studies referring to adults with the main focus being T2DM, nutrition and information behaviour or practice (need, seeking, use) in its broadest sense (i.e. need, seeking, use of any artefact that could be a potential source of nutrition information). All study types that reported primary research were included. Studies that did not specify the type of diabetes although the majority of participants were likely to have T2DM were included.

Studies were excluded if their main focus was not related to adults with T2DM, nutrition and information behaviour or practice, if the study was not in English and did not report primary research. Studies that had their main focus as other types of diabetes such as T1DM or gestational diabetes were excluded. Studies that reported secondary research such as systematic reviews were excluded.

Data extraction and synthesis

In a preliminary phase of the review two members of the supervisory team independently extracted data from a proportion of the studies. This informed the process for the data collection process, selection process and risk of bias assessment in the study.

To facilitate critical appraisal, studies were grouped according to the methodologies quantitative, qualitative and mixed methods. Data were extracted into a table that was created for this purpose. Headings in the table were authors, year, research design and method, recruitment setting, country in which the study took place, age of the participants, sex and sample size, type of diabetes³, aims of the study, the main themes from the findings that related to nutrition information activities of people with T2DM, the materials referred to in the study and limitations. The results from the quantitative studies were translated into narrative summaries and tabulated in Excel. The findings from the qualitative studies were tabulated alongside these. Analysis of the studies was undertaken using categories derived from the aims of the study (deductive) as well as new categories (inductive) that emerged from the analysis. The categories were summarised, connections between categories were identified and themes were developed.

Each study was subjected to critical appraisal to assess the potential risk of bias using a tool devised for the methodology of the study as advised by NICE (2014). The findings of the appraisal were extracted into a table enabling reporting of potential quality issues across a range of methodologies (Hong QN et al., 2018; Pluye, Gagnon, Griffiths, & Johnson-Lafleur, 2009). Studies were rated green if there were no or few concerns about the quality of the studies, amber if there were some concerns and red if there were major concerns that suggested bias that would lead to questioning the study conclusions. All studies were critiqued for the presence of a clear aim, research question or objectives and if the data collected enabled addressing these. Qualitative studies were critiqued for the relevancy of the data sources and strategy, the analysis process, the relevancy of the findings and the researcher influence. Quantitative studies were critiqued for their sampling and recruitment processes, the measurements and/or tools used, group comparisons and randomisation processes (for randomised controlled trials), completeness of data and response rate for those using questionnaires. Mixed methods studies as well as relevant aspects of the above were critiqued for the relevancy of the design and the integration of the findings.

2.3 Findings

The number of studies identified from the search process are summarised below in the PRISMA flow diagram. Eight thousand, one hundred and thirty-five records were identified through the database search. Of these 892 were found to be duplicates. This left 7243 records. Citation searches yielded

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³ Some studies did not specify the type of diabetes of their participants. Some studies included people with T1DM or pre-diabetes. In these cases studies were included where there was a likelihood that the majority of participants had T2DM.

four publications (forward citations from key sources n=3, and citation checks n=1). Therefore 7247 records were screened for eligibility. Of these 7174 were excluded after title and abstract screening. The remaining 71 records had their full text publications assessed for eligibility. All full texts were obtained. Of these 43 were excluded. The main focus of 19 was not information behaviour or practice, while the main focus of 10 publications was not diabetes and not about adults with T2DM and the main focus of 14 publications was not about diet or nutrition. Twenty-eight publications were included in the final review.

Figure 1 PRISMA 2009 Flow Diagram showing the number of studies identified at each stage of the process

Identification	Total records identified through data base searching (n= 8135)		
	Records after duplicates removed (n=7243)	•	Excluded duplicates N= (892)
	Records after duplicates removed (n=7243)		
		—	Additional records identified through Forward citations (n=3) Citation checks (n=1) Total from citation searches (n=4)
Screening			
	Records screened (n= 7247)		Records excluded after title and abstract screening (n=7174)
Eligibility	Full-text publications assessed for eligibility (n=71)	•	Full-text publications excluded (43) Main focus not information behaviour or practice (19) Main focus not diabetes and not about adults with type 2 diabetes (10) Main focus not about diet or nutrition (14) Not able to obtain (0)
Included	-		
	Total studies included (n=28)		

2.3.1 Description of the included studies

Twelve studies used a quantitative methodology, 14 studies followed a qualitative methodology and two used mixed methods. The summary table can be found in appendix 3.

Methods used in the studies.

The most frequent methodology used in the quantitative studies was a cross-sectional design utilising a questionnaire (8 studies) (Ball et al., 2012; Fitzgerald, Damio, Segura-Pérez, & Pérez-Escamilla, 2008; Gray, Petersen, Clifton, & Keogh, 2014; Kessler & Wunderlich, 1999; Pinto & Braz, 2016; Searle & Ready, 1991; Waller & Tzeng, 2011; Watson & DuFourd, 1992). Four undertook quasi-experimental approaches investigating the impact of information activities but without controls or randomization (Byrne et al., 2017; Herrejon, Hartke, Scherer, & Chapman-Novakofski, 2009; Martins, Ambrosio, Nery, Aquino Rde, & Queiroz, 2014; Waki et al., 2015).

The most frequent method used in the qualitative studies (n=15) was focus groups (7 studies, 6 just used focus groups) (Beverly, Miller, & Wray, 2008; Breland, McAndrew, Gross, Leventhal, & Horowitz, 2013; Lee, Willig, Agne, Locher, & Cherrington, 2016; Meyfroidt et al., 2013; Mphwanthe, Carolan, Earnesty, & Weatherspoon, 2021; Murrock, Taylor, & Marino, 2013). Miller, Probart, and Achterberg (1997) used focus groups and in depth interviews while Lawrence, Reynolds, and Venn (2017) used group interviews. Of the remaining 7 studies, 6 used interviews (Albright, 1994; Ball et al., 2015, 2016; Matpady et al., 2020; Scott, 1997; Wermeling, Thiele-Manjali, Koschack, Lucius-Hoene, & Himmel, 2014) and one used a diary approach (Cradock et al., 2021).

Frandsen and Kristensen (2002) utilised a mixed methods approach integrating the findings from a questionnaire with focus groups.

Overview of findings from the critical appraisal

The critical appraisal for each study is summarised in appendix 4. Almost all the studies had methodological issues that called into question the trustworthiness of the findings (qualitative and mixed methods studies) or potential bias (validity and reliability) in the findings presented. However, as the majority of these were considered minor, all the studies were included in the review following the critical appraisal process.

Twelve out of the 15 qualitative studies had minor methodological issues that may have impacted on the credibility, dependability, transferability of the findings and did not show sufficient awareness of the researchers' impact on the environment (reflexivity). The critical appraisal process identified eleven studies with weaknesses relating to the participants/data sources that may have impacted on the potential transparency of the findings (Albright, 1994; Ball et al., 2015; Matpady et al., 2020; Meyfroidt et al., 2013; Scott, 1997; Wermeling et al., 2014); credibility of the findings (Ball et al., 2015, 2016; Cradock et al., 2021; Lawrence et al., 2017; Meyfroidt et al., 2013); transferability of the findings (Albright, 1994; Meyfroidt et al., 2013; Mphwanthe et al., 2021; Murrock et al., 2013). One qualitative study did not provide a sufficiently clear description of the process for analysis in order for the trustworthiness of the findings to be judged (Scott, 1997). Four qualitative studies did not make a reference to the researcher's impact on the study process (reflexivity) (for example the use of field notes to record incidents) (Albright, 1994; Cradock et al., 2021; Miller et al., 1997; Wermeling et al., 2014).

In the quantitative studies, just one study appeared to not have any methodological issues causing concern over bias (Waki et al., 2015), although this was a small study and so the potential validity and reliability of the findings were considered. For six studies recruitment process concerns were identified that potentially impacted on the validity of the findings (Ball et al., 2012; Fitzgerald et al., 2008; Kessler & Wunderlich, 1999; Searle & Ready, 1991; Waller & Tzeng, 2011; Watson & DuFourd, 1992). The quality appraisal raised concerns over the measurements used in three quantitative studies that potentially impacted on the reliability of the findings (Byrne et al., 2017; Gray et al., 2014; Pinto & Braz, 2016) and for three studies there were concerns about the outcome data that impacted on the potential validity of these (Byrne et al., 2017; Herrejon et al., 2009; Martins et al., 2014).

There were a number of issues in the mixed methods study undertaken by Frandsen and Kristensen (2002) relating to data analysis across the qualitative and quantitative parts of the study and some data from one group of participants is missing that potentially impacted on the trustworthiness and reliability of the study.

Participants

The sample sizes of the quantitative studies ranged from 939 (Ball et al., 2012) to 5 participants (Waki et al., 2015), and the studies using a qualitative design ranged from 60 (Beverly et al., 2008) to

10 participants (Ball et al., 2015, 2016). The sample size of the mixed methods study was 123 (Frandsen & Kristensen, 2002).

Most of the studies included only participants with T2DM, however some studies did not clarify the type of diabetes or included other types of diabetes (these studies were included if there was an indication that the majority of participants had T2DM). While Herrejon et al. (2009) did not clarify the diabetes diagnoses of their participants, the website being evaluated was aimed at people who had T2DM; the participants in Kessler and Wunderlich (1999) had T1DM or T2DM, although the authors note that the majority of the 190 participants had T2DM; of the 12 participants in the study by Lawrence et al. (2017), 10 had T2DM and 2 had pre-diabetes; Breland et al. (2013) included black and Latino adults with diabetes, a population group at the time of the research with a high prevalence of T2DM and so the authors comment that the majority of the participants are likely to have T2DM.

The age of the participants in the studies ranged from under 25 years (Ball et al., 2012) to 85 years (Meyfroidt et al., 2013). While most studies explored T2DM across life stages, one study focussed on older adults only (Albright, 1994) (age range 65 to 84 years). Most studies included both female and male participants while four studies recruited only females (Miller et al., 1997; Murrock et al., 2013) and one study only males (Lee et al., 2016).

Just one study (Scott, 1997) was set in the UK. Eleven studies were set in the USA while four were based in Australia (Ball et al., 2015, 2016; Ball et al., 2012; Gray et al., 2014) and one study included participants from a number of countries (France, Germany, Spain, UK, USA) (Frandsen & Kristensen, 2002); four were set in Europe: Portugal (Pinto & Braz, 2016), Belgium (Meyfroidt et al., 2013), Germany (Wermeling et al., 2014), Ireland (Cradock et al., 2021). Other studies were set in Brazil (Martins et al., 2014), Canada (Searle & Ready, 1991), India (Matpady et al., 2020), Japan (Waki et al., 2015), Malawi (Mphwanthe et al., 2021) and New Zealand (Lawrence et al., 2017).

Some studies focused on specific populations. For example, older people (Albright, 1994; Byrne et al., 2017), or minority ethnic groups with higher incidence of T2DM, for example Latinas (Fitzgerald et al., 2008); African Americans (Murrock et al., 2013; Waller & Tzeng, 2011); black and Latino adults (Breland et al., 2013); and people of West Indian origins (Scott, 1997). Other studies focused on the length of time with diabetes; for example Ball et al. (2015) and Ball et al. (2016) focused on those

who were newly diagnosed; and on diabetes management, for example Meyfroidt et al. (2013) focused on those with poor diabetes control.

Participants were recruited from a range of settings: participants from twelve studies were recruited whilst accessing diabetes care or support (Albright, 1994; Byrne et al., 2017; Cradock et al., 2021; Gray et al., 2014; Herrejon et al., 2009; Kessler & Wunderlich, 1999; Martins et al., 2014; Matpady et al., 2020; Pinto & Braz, 2016; Scott, 1997; Waki et al., 2015; Watson & DuFourd, 1992); while six studies recruited participants from records held by diabetes care organisations (Ball et al., 2015, 2016; Ball et al., 2012; Beverly et al., 2008; Frandsen & Kristensen, 2002; Searle & Ready, 1991) and six from the wider community (Beverly et al., 2008; Breland et al., 2013; Fitzgerald et al., 2008; Miller et al., 1997; Waller & Tzeng, 2011; Wermeling et al., 2014); however three studies recruited participants while accessing general healthcare (Meyfroidt et al., 2013; Murrock et al., 2013; Wermeling et al., 2014), two recruited participants from general healthcare organisations (Lawrence et al., 2017; Lee et al., 2016) and one from participants taking part in a larger study (Mphwanthe et al., 2021).

In summary, the studies identified in the literature utilised both qualitative and quantitative designs with a range of methodologies. Almost all participants had T2DM, the studies included both male and female participants with a wide range of ages and from a range of population groups. The majority of the studies were undertaken outside the UK with participants recruited from both healthcare and community diabetes and non-specific diabetes settings. The studies identified were wide ranging and their heterogeneous nature meant that meta-analysis was not appropriate. Therefore, findings are presented narratively.

2.3.2 Focus of the studies.

All studies had a focus on nutrition information activity, all exploring or investigating nutrition information sources used by people with T2DM. For nine studies the focus was on the experiences of the nutrition information activity of the participants (Albright, 1994; Ball et al., 2015, 2016; Ball et al., 2012; Lawrence et al., 2017; Meyfroidt et al., 2013; Mphwanthe et al., 2021; Scott, 1997; Wermeling et al., 2014). Albright (1994) studied the experiences of dietary management; Ball et al. (2012), Ball et al. (2015, 2016) and Wermeling et al. (2014) explored patient perceptions of nutrition care; Lawrence et al. (2017) explored the dietary perceptions held by the participants; Mphwanthe et al. (2021) explored barriers and facilitators to a healthy diet; Meyfroidt et al. (2013) explored the

experiences of accessing and using nutrition information; Scott (1997) explored patients experiences of nutrition service.

However, for the remaining 20 studies the focus was on the impact of nutrition information behaviour/practice on dietary behaviours (12 studies): (Beverly et al., 2008; Breland et al., 2013; Cradock et al., 2021; Fitzgerald et al., 2008; Frandsen & Kristensen, 2002; Gray et al., 2014; Kessler & Wunderlich, 1999; Lee et al., 2016; Martins et al., 2014; Miller et al., 1997; Murrock et al., 2013; Waller & Tzeng, 2011). While 11 studies explored the impact of nutrition information behaviour/practice on knowledge (Breland et al., 2013; Fitzgerald et al., 2008; Gray et al., 2014; Herrejon et al., 2009; Kessler & Wunderlich, 1999; Martins et al., 2014; Matpady et al., 2020; Miller et al., 1997; Pinto & Braz, 2016; Waller & Tzeng, 2011; Watson & DuFourd, 1992) three studies explored the impact of nutrition information behaviour/practice on clinical outcomes (Byrne et al., 2017; Pinto & Braz, 2016; Waki et al., 2015) and three on further nutrition information behaviour/practice (Gray et al., 2014; Kessler & Wunderlich, 1999; Searle & Ready, 1991). Eight studies explored more than one impact for example Pinto and Braz (2016) explored the impact on clinical outcomes and knowledge and Fitzgerald et al. (2008), Martins et al. (2014), Waller and Tzeng (2011), Breland et al. (2013) and Miller et al. (1997) explored the impact on knowledge and dietary behaviours while Gray et al. (2014) and Kessler and Wunderlich (1999) explored the impact of nutrition information behaviour/practice on further nutrition information behaviour/practice as well as on knowledge and dietary behaviours.

2.3.3 Sources of nutrition information

The wide range of nutrition information sources that were identified in the included studies were categorised into three types; people, written information or media (see appendix 3 for the sources identified by each study according to these categories). These are discussed below.

People as a nutrition information source

Seventeen studies explored or identified health care professionals (HCPs overall, GPs/doctors, dietitians, nurses, pharmacists) as a source of nutrition information, of these seven reported information provided by GPs and doctors (Ball et al., 2012; Frandsen & Kristensen, 2002; Meyfroidt et al., 2013; Mphwanthe et al., 2021; Murrock et al., 2013; Searle & Ready, 1991; Wermeling et al., 2014), six reported information provided by dietitians (Ball et al., 2016; Fitzgerald et al., 2008; Meyfroidt et al., 2013; Murrock et al., 2013; Pinto & Braz, 2016; Searle & Ready, 1991), one reported

nurses as a source of nutrition information (Mphwanthe et al., 2021) and one reported that pharmacists were a source of nutrition information (Frandsen & Kristensen, 2002).

Some studies found that the advice from HCPs was considered the most valuable source by participants, however, they all used different methodologies of data collection and were undertaken in different countries with likely different health systems. For example Meyfroidt et al. (2013) who undertook focus groups with people with diabetes in Brussels whose control was considered poor, found that while participants used a wide range of sources of information, information from GPs and HCPs was considered reliable and from a GP or dietitian the most meaningful. Matpady et al. (2020) in their study in India which utilised qualitative interviews with participants who had recently completed a diabetes self-management questionnaire found that advice from an HCP was an enabler to their self-management, however, only a few (7 out of 35 participants) had seen an HCP. Watson and DuFourd (1992) undertook a survey of 101 people with T2DM attending a diabetes programme in the USA. They found that the information received from an HCP (which they refer to as 'instruction') led to improved knowledge on diet and diabetes.

Studies also identified a variation in experiences with HCPs in the delivery of nutritional information. Lawrence et al. (2017) undertook group discussions with 12 people with T2DM recruited from community settings using a range of recruitment methods in New Zealand. They found that participants used a wide range of sources but experiences with HCPs were varied across the group, some had positive experiences while others refer to a feeling of being 'betrayed' by HCPs as they were not given sufficient information in a timely way that would enable them to manage their T2DM. Frandsen and Kristensen (2002) also identified dissatisfaction with information from HCPs. However, their study utilised a mixed methods approach, with 123 people with T2DM receiving drug treatment, incorporating qualitative focus groups with 'in group' questionnaires. Participants were recruited from France, Germany, Spain, UK and the USA. They found that the level of dissatisfaction with the amount of information participants received led to using information from sources that may include non-evidence-based information (newspapers and magazines) as well as other sources that were likely to include evidence based information (pharmacy and diabetes patient organisations).

A more frequent finding from the studies which explored advice from HCPs was that information was not always provided and when it was it was found to be limiting. For example Murrock et al. (2013) found that the advice received from a dietitian or GP was not sufficiently detailed to enable

their participants to be able to make decisions about their diets when eating with family and friends. While this focus group study, with 24 African American women attending a family practice centre at an urban Midwest hospital in USA, had limitations in the recruitment being from one setting and so may not represent the views of African American women beyond the specific family practice, other studies also found issues with the advice given by HCPs. A common finding was that information was overwhelming (Albright, 1994; Ball et al., 2015; Breland et al., 2013) and conflicting (Mphwanthe et al., 2021; Pinto & Braz, 2016). Ball et al. (2015) undertook 10 telephone interviews with participants who were newly diagnosed with diabetes from a wide geographical area across Queensland, Australia. They found that the experience of receiving overwhelming and information that appeared to conflict with other sources with insufficient time allowed for the consultation led to a feeling of confusion and a lack of further engagement in obtaining guidance from HCPs and in dietary selfmanagement. Breland et al. (2013) undertook four focus groups with black and Latino adults from East Harlem, New York and found that advice from HCPs was abstract and sporadic. This concurs with Albright (1994), whose interviews with older people recruited from non-profit community based hospital in San Francisco bay area the majority of whom were women, found that the advice from HCPs when given was found to be overwhelming. However, Pinto and Braz (2016) also found that older people with diabetes experienced limitations with the advice from an HCP (GP or dietitian); they used a questionnaire with participants recruited from those attending a consultation at a diabetes clinic in Faro, a Portuguese region of the Algarve, and found that older people who had received advice in this way found the guidance to be conflicting. Mphwanthe et al. (2021) in their focus group study in Malawi found that the participants recruited from urban environments experienced inconsistent and conflicting advice from HCPs, while those from semi-urban environments did not report this concern.

Impact of advice from HCPs

Some studies went on to explore the potential impact of advice that their participants had found to be limiting, for example, finding it was not individualised (Breland et al., 2013; Matpady et al., 2020; Scott, 1997) and that it did not take into account traditional foods (Lee et al., 2016; Scott, 1997). Lee et al. (2016) undertook focus groups with non-Hispanic black men living with T2DM in the Birmingham-Hoover Metropolitan Area in the USA who were recruited from a hospital providing public safety-net health system (to the uninsured). They found that the foods that are encouraged by HCPs as being suitable for people with diabetes do not include the foods that they traditionally eat and are expensive or not available. Similarly, Scott (1997), who undertook qualitative interviews with 24 West Indian and white British people with T2DM (sex not recorded) recruited from general

practices in the UK. They found that participants had difficulty in following advice, the guidance was not geared towards them especially when they lived in an area with fewer West Indians. Cooking methods advised by HCPs assumed the following of recipes which was not their usual practice and eating of foods that they did not normally eat made the advice difficult to apply. Participants interpreted the advice making their own decisions that could potentially lead to worsening diabetes outcomes impact on the way that their diabetes was managed. These findings across different countries suggest that challenges for HCPs in delivering individualised advice that people with T2DM can apply to their own lives are not restricted to one setting.

Often advice was not available from GPs (Pinto & Braz, 2016) or accessed (Matpady et al., 2020). For example, Matpady et al. (2020) found that most of their participants preferred to access advice from their social network. However Meyfroidt et al. (2013) and Ball et al. (2012) found that GPs were a preferred source of nutritional advice. For example Ball et al. (2012) in their cross-sectional online survey with members of Diabetes Australia Queensland in Australia who had T2DM found that while the majority of participants felt that it was part of the GP role to deliver nutritional advice, less than half of those surveyed had experienced the advice. However, of those who had experienced the advice almost all were satisfied with the advice that was given. This experience was in contrast to other studies which, as with advice given by HCPs in general, found that many were dissatisfied as the advice was often basic and did not enable participants to apply the information to their own diets (Murrock et al., 2013; Wermeling et al., 2014). For example Wermeling et al. (2014) analysed data from 35 pre-recorded interviews with people with T2DM recruited from a wide range of health and social settings. They found that while the GP was key in providing guidance on how to manage their diet and diabetes, often this did not take into account their customs and traditions.

Studies identified that information from a dietitian was found to be helpful (Ball et al., 2016; Fitzgerald et al., 2008). For example Fitzgerald et al. (2008) undertook a questionnaire study with 201 people with cultural ties to Latin America, recruited from community settings in Connecticut, USA, 100 of whom had T2DM. They found that seeing a dietitian helped them to self-manage, particularly in encouraging them to use food labels. Ball et al. (2016) in their study exploring the experiences of newly diagnosed T2DM with nutrition care received from a dietitian (data collected as part of Ball et al., 2015) found participants reported that they had become more confident in their nutritional choices having seen a dietitian. However, a common theme from this study was that the nutrition care tended to be directive. Limitations in the support from dietitians was found in other studies. For example Pinto and Braz (2016) found that advice from a dietitian was not always

available. Searle and Ready (1991) implemented a cross -sectional survey with a random selection of 479 people with T2DM from provincial records in the USA. They found that while most participants accessed advice from a dietitian, information about eating with diabetes was sought from other sources such as the GP, media and the Canadian Diabetes Association.

A number of similar and contrasting findings have been identified. Overall advice from specific HCPs was trusted and valued, HCPs who are trained to provide nutritional advice enabled participants to self-manage their diabetes, however, advice was not always available and did not always meet the needs of participants. The studies being methodologically heterogenous, undertaken with a range of participants from different settings and countries suggests that these findings are widespread common occurrences.

Other sources of information included group education, peer groups, family and friends, diabetes organisations and the participants themselves. Five studies explored the effect of group education (Byrne et al., 2017; Martins et al., 2014; Murrock et al., 2013; Waller & Tzeng, 2011; Watson & DuFourd, 1992); one study identified peer groups as a source of information (Mphwanthe et al., 2021); three identified family and friends (Beverly et al., 2008; Lawrence et al., 2017; Meyfroidt et al., 2013); one study identified diabetes organisations (Frandsen & Kristensen, 2002); and one study identified the participants themselves as a source of information. This included feedback information from blood test results and how participants were feeling (Lawrence et al., 2017).

Group education

Three studies found that group education increased knowledge and provided the skills to enable self-management (Byrne et al., 2017; Martins et al., 2014; Waller & Tzeng, 2011). Byrne et al. (2017) undertook a retrospective review of clinical outcomes following attendance at a follow up healthy teaching kitchen of 155 people attending a diabetes self-management education and support programme in the USA. They found that with an increase in attendance at the healthy teaching kitchen, there was a significant improvement in diabetes outcome measures, although the authors comment on the sample size and that confounding variables such as exercise, medication and carbohydrate consumption were not collected. Waller and Tzeng (2011) undertook an exploratory pilot study with 60 people with T2DM recruited from urban African American churches in Michigan and Ohio, USA on the extent to which they had received information on the glycaemic index and the impact of this information. They found that the majority had attended educational programmes on diet and diabetes, however only half had received guidance on glycaemic index. Where this had

been provided there was a greater knowledge and ability to apply the information. Martins et al. (2014) assessed food knowledge and T2DM and measured the HbA1c⁴ of 21 people with T2DM before and after attending a four-hour carbohydrate-counting course held at a hospital in São Paulo, Brazil. They found that the HbA1c had improved significantly one year after, however, while there were ongoing misconceptions about the diet overall understanding had improved. These studies suggest that practical skills development can improve knowledge on how to self-manage, but that this is not always necessary in the ability to self-manage. Learning how to look after diabetes through practical activities can improve the ability to self-manage per se.

One study found that diabetes peer support groups facilitated healthy eating in their participants. Mphwanthe et al. (2021) in their focus group study in Malawi found that the urban participants felt that peer support groups that they had attended facilitated their healthy eating behaviours. The support groups were emphasised as sources of positive support in the eco-maps drawn by participants during the focus group sessions. Participants reported teaching each other about what to eat and sharing information, however this source of information was not raised by the semi-urban participants in their focus groups. While these groups were facilitated by a retired nurse, they imply that HCPs may not always be necessary to deliver nutritional advice for T2DM and as suggested above they may not have the skills to facilitate the application of information to individual's own settings.

Studies found that family and friends can be supportive in helping people to manage their diabetes and may be a preferred choice of nutritional advice (Matpady et al., 2020) and may assist with dietary behaviours (Beverly et al., 2008). For example, Beverly et al. (2008) explored the impact of the spousal relationship on people with T2DM being able to self-manage. The study utilised a qualitative approach using focus groups involving couples, aged 50 and over, managing T2DM. Groups were separated into those with T2DM and the spouses of those with T2DM. The findings suggest an overall positive impact of the spouse on supporting the person with T2DM. However, barriers to food choice and feelings of control were identified. Thus, recommendations while supporting the concept of working with spouses of those with T2DM in order to assist selfmanagement confer that support and education is needed for spouses to maximise their potential value in assisting people with T2DM to self-manage.

⁴ Diabetes UK define HbA1c as 'your average blood glucose (sugar) levels for the last two to three months'. (https://www.diabetes.org.uk/guide-to-diabetes/managing-your-diabetes/hba1c)

Information from people (HCPs, in a group setting, family and friends) were the most common sources of information. While information from GPs was often valued, a wide range of heterogenous studies suggested that the experiences of nutrition information were often met with dissatisfaction. Group settings appeared to improve diabetes outcome measures and be met with satisfaction and family including spouses were found to be a valued resource, however guidance for the family in providing this support was identified.

Written sources of nutrition information

Written sources of nutrition information were identified by ten studies (Albright, 1994; Ball et al., 2012; Beverly et al., 2008; Byrne et al., 2017; Cradock et al., 2021; Frandsen & Kristensen, 2002; Lawrence et al., 2017; Miller et al., 1997; Scott, 1997; Searle & Ready, 1991). Three studies identified books, magazines and newspapers (Beverly et al., 2008; Frandsen & Kristensen, 2002; Lawrence et al., 2017). Five studies explored food labels (Fitzgerald et al., 2008; Gray et al., 2014; Kessler & Wunderlich, 1999; Lawrence et al., 2017; Miller et al., 1997). While these resources were developed for people with T2DM, and one study identified the value of an individually created resource (Cradock et al., 2021).

Written information was often referred to in general terms, however, some studies referred to specific types of written information, for example Byrne et al. (2017) and Scott et al. (1997) referred to participants using recipes, Albright (1994) referred to food exchange lists as being sources of information, Searle and Ready (1991) referred to meal plans and cook books and Beverly et al. (2008) found some participants had obtained information 'about the food' from books. However, written information for people with T2DM was also referred to in terms of an artefact as opposed to a source of specific type of information. For example, Byrne et al. (2017) referred to the use of handouts in their teaching sessions, and Ball et al. (2012) identified that most participants would like GPs to provide written advice, to help them manage their diabetes. Frandsen and Kristensen (2002) found that books about diet and nutritional information were the preferred choices in the European countries, while videos were preferred by participants from the USA. Although preferences and specific usage of written information were identified by some of these studies, the nonspecific nature in which they were often referred to identifies the tacit nature and use of written information for people with T2DM.

One study (Cradock et al., 2021) referred to the process of the participants developing their own written artefact to help them manage their diabetes in the form of a written diary. The study was undertaken in Ireland with 18 people with T2DM attending a lifestyle intervention programme. The reflective diary sensitised and helped participants to identify potential ways in which they could change their diets. This study suggests that the use of information created by someone with T2DM for their own use in a written format may to go beyond being a source of information into a method of self-management.

Four studies explored the use of food labels by people with T2DM (Gray et al., 2014; Kessler & Wunderlich, 1999; Lawrence et al., 2017; Miller et al., 1997). Gray et al. (2014) combined the use of a survey which assessed knowledge about sodium in the diet and for people with T2DM, with a food frequency questionnaire for sodium intake with 124 people with T2DM attending a diabetes centre in Adelaide, South Australia. They found that the majority read labels, were aware of common highsalt foods and use of low-salt products. However, most did not know the maximum recommended intake of salt or that foods such as bread and cheese are high in salt. A lower salt intake was found in men who used food labels to make decisions about what to eat when compared to those who did not use food labels however the overall excretion of sodium in the urine was still high. Although this study reinforces the potential value of food labels to assist in the dietary management of T2DM, the authors note that the timing of the collection of the urine sample may have impacted on the findings. Similarly, Kessler and Wunderlich (1999) also found food labels were commonly used in their study with 190 people with T1 and T2DM (the authors state that the majority were thought to have T2DM), attending American Diabetes Association patient education programmes. They found that, although almost all used food labels, many did not understand the difference between sugar and carbohydrate or understand the information about portion sizes. Miller et al. (1997) also found misunderstandings about food labels in their study using focus groups and interviews with 27 women with T2DM recruited from a rural community in the USA. They found that the participants found using food labels to help them make decisions about what to eat difficult, they did not understand the percentage energy, the difference between saturated and unsaturated fat and the difference between carbohydrate and sugar. Food labels appear to be frequently used by people with T2DM but as they were developed for the general population, these studies suggest that their value to people with T2DM is limited.

Written artefacts containing nutrition information were widely used by participants across the studies. However, the nonspecific nature of the reporting in the studies limits a definitive summary

as to their potential value over and above their wide usage. The creation of an individual written artefact appears to be of value, and this is contrasted with the attempted use of food labels by many study participants to help them manage their diabetes.

Media as a source of nutrition information

Two studies identified broadcast media as a source of nutrition information (Beverly et al., 2008; Meyfroidt et al., 2013), while four studies identified the internet (Beverly et al., 2008; Herrejon et al., 2009; Lawrence et al., 2017; Meyfroidt et al., 2013), one explored a specific website (Herrejon et al., 2009) and one explored the use of an app (Waki et al., 2015).

Waki et al. (2015) explored the use of an app with visual functionality. Their project involved five people with T2DM aged 55.9 +/- 10.8 SD who had taken part in an earlier study involving development of the app in Japan. This study involved the assessment of the use of a photo of food eaten to assess the nutritional value of what had been consumed. While the system was found to be easy to use it was not found useful by all as the system did not include the foods that were consumed. Those that found the app useful had an improved HbA1c.

Broadcast media was found to be one of many sources used by participants to manage their diabetes (Beverly et al., 2008; Lawrence et al., 2017; Matpady et al., 2020; Meyfroidt et al., 2013), however, sometimes these sources were only referred to in passing. For example, Beverly et al. (2008) stated 'information came from sources including books, magazines, newsletters, newspapers, television...' and Lawrence et al. (2017) stated 'other reported sources of dietary information were magazines, television, newspapers,...'. However, Matpady et al. (2020) found that television and commercials were a common source of nutrition information for people with T2DM particularly in how to incorporate healthy foods into their diets. While Meyfroidt et al. (2013) also found television a common source with it being identified as the third most used source and useful as an adjunct to the information provided by HCPs.

The internet was found to be one of the sources used by participants although it was not as highly valued as GPs and dietitians (Beverly et al., 2008; Lawrence et al., 2017; Meyfroidt et al., 2013). However Herrejon et al. (2009) explored the impact of an interactive website aimed at people with T2DM. The study which took place in the USA involved the use of a questionnaire and quantitative assessment of data individuals who accessed the website in the first 2 weeks. These individuals were included if they also completed at least one demographic information question and one or more

interactive knowledge or skills question. One hundred and four sets of data were collected in this way. They found that using the website resulted in improved knowledge about carbohydrate foods. Also, it was noted that the interactive aspect ('making a plate' skills activity) was used more often than the 'carbohydrate in foods' activity.

The variable reporting of media provides challenges in identifying the value of these sources to people with T2DM. The lack of specificity of the findings may suggest that they are an adjunct to advice from HCPs. However, their ability to enable practical engagement by visually being able to see how to undertake an activity may suggest that they are a source that is worthy of further investigation.

Conclusion

Although HCPs were found to be the main source of nutrition information explored by the studies, many other sources were identified and explored using different artefacts and modalities. While accessing information from different sources may provide conflicting information this variation in sources also indicates a potential challenge in accessing, using and interpreting a wide range of sources that were not necessarily designed for use by people with T2DM. Different skills are likely to be needed to be able to access support from different sources i.e. from people, written information and media in order to piece together the information needed to self-manage.

2.3.4 Types of nutrition information

The type of nutrition information referred to varied widely across the studies. Some studies did not refer to specific nutrition information or advice but instead used broad terms such as: dietary regimen (Albright, 1994); nutrition care (Ball et al., 2012); healthy diet (Ball et al., 2016); healthful diet (Beverly et al., 2008); diet information needs (Meyfroidt et al., 2013); dietary instruction (Watson & DuFourd, 1992); lifestyle counselling and weight management (Wermeling et al., 2014). This lack of specificity as to what constitutes nutritional information or advice was highlighted by Frandsen and Kristensen (2002), when exploring factors affecting dietary compliance. They found that while some participants received detailed advice and meal planning, guidance on foods to eat less of and foods to eat more of, other participants had received general 'broad' advice to simply lose weight and to eat healthy foods. Although the study found that participants were motivated and aimed to follow the dietary advice they were given, most were dissatisfied with the information as it did not explain the reasons behind the different types of information and why it was important to their diabetes management.

Eighteen out of the 26 studies gave some indication as to the focus of nutrition information in their studies, however these topics varied across the included studies. Studies explored information about the food provisioning process of being able to access healthy foods (Ball et al., 2015; Breland et al., 2013; Lee et al., 2016); of meal planning (Frandsen & Kristensen, 2002; Herrejon et al., 2009; Murrock et al., 2013; Searle & Ready, 1991); how to prepare healthy foods (cooking skills and recipes) (Ball et al., 2015; Byrne et al., 2017; Scott, 1997; Searle & Ready, 1991); portion sizes (Breland et al., 2013; Kessler & Wunderlich, 1999; Martins et al., 2014; Waki et al., 2015); what foods contain carbohydrate (including sugar and glycaemic index) (Lawrence et al., 2017; Martins et al., 2014; Miller et al., 1997; Searle & Ready, 1991; Waller & Tzeng, 2011); carbohydrate counting (Herrejon et al., 2009; Martins et al., 2014; Miller et al., 1997; Murrock et al., 2013); fats (Miller et al., 1997); food labels and health claims (Ball et al., 2015; Fitzgerald et al., 2008; Gray et al., 2014; Kessler & Wunderlich, 1999; Lawrence et al., 2017); eating out (Lawrence et al., 2017; Lee et al., 2016; Pinto & Braz, 2016); calories and weight loss (Searle & Ready, 1991; Waki et al., 2015).

The extensive list of potential topics to cover in nutritional advice for T2DM diabetes indicates that nutrition information for T2DM is complex and suggests that there may be challenges in being able to deliver and follow nutritional advice.

The sizeable proportion of studies that did not identify specific nutrition information topics may also indicate a lack of awareness as to the large number of topics that people with T2DM need in order to self-manage.

2.3.5 Reasons for people with T2DM accessing nutrition information

There were two main themes that arose out of the reasons for people with T2DM accessing nutrition information in the included studies. These were to be able to self-manage their diabetes and to be able to apply the nutrition information to their own food provisioning activities.

Self-management

The main reason for accessing nutrition information was so that participants could self-manage their diabetes. For example Beverly et al. (2008) found that, in order to be able to self-manage, participants commonly needed to utilise information from a wide range of sources in order to better understand their diabetes and to be able to make their own decisions; Ball et al. (2015) found that

the information was needed in order to be able to modify what was eaten, this formed part of the process for self-management; and Meyfroidt et al. (2013) found that participants wanted information in order to self-manage. However, some studies referred to specific diabetes related outcome measures that participants wanted to achieve. For example, Albright (1994) found that their participants reported that they needed to 'figure' out the advice so that they could maintain a healthy weight; Pinto and Braz (2016) found that participants wanted to be able to apply nutrition information to their day-to-day lives to improve their diabetes control; and Gray et al. (2014) found that most participants said that they regularly or sometimes checked food labels for salt content to help to reduce salt consumption and blood pressure. The range of studies across methodologies and countries included in this review (for example Albright, 1994, USA, qualitative study; Gray et al., 2014, Australia, cohort study; Pinto & Braz, 2016, Portugal, cross-sectional) has identified a wide range of self-management decision-making processes, from being able to understand and to look after their diabetes to specific aspects of self-management including being able to make decisions about what to eat, maintaining a healthy weight, maintaining diabetes control and blood pressure.

Food provisioning

While the studies identified above referred to general aspects of self-management and being able to make decisions, five studies also referred to specific sources of information used, and decisions made in order to be able to self-manage their diabetes. In these studies, there was a greater focus on the ability to apply nutritional advice to their own food provisioning processes, that is to be able to make decisions on what to eat. For example Martins et al. (2014) explored the incorporation of carbohydrate counting following attendance at a course in order to manage the participants, finding that use of the method enabled greater flexibility in their food choices; Miller et al. (1997) found that participants wanted to be able to use information about carbohydrate and fat in order to be able to incorporate a food into a meal plan; Ball et al. (2016) found that participants wanted and needed information on what foods to eat and to avoid, how to read food labels and information about portion sizes to be individualised so that they could make decisions based on what they normally ate. Matpady et al. (2020) found that their participants used the information in order to make their menus healthy. For other studies the information was needed in a form that enabled budgeting, and planning meals alongside family needs (Murrock et al., 2013) and when circumstances were challenging when on a low income (Breland et al., 2013).

Summary

Analysing the studies from the point of view of what participants wanted to achieve by their nutrition information/practice identified the widespread desire to be able to self-manage their diabetes and to be able to adapt the advice to their own food choices and situations. Some studies identified specific information such as being able to use food labels and understand how much carbohydrate was in a food and others underline the difficulties in being able to 'self-manage' in challenging situations alongside family members and when resources are limited. Both the lack of specificity of the information needed in order to be able to self-manage identified in some studies, and the detailed knowledge needed in order to apply the advice to their own settings, indicates the challenges that people with T2DM face when wanting to look after themselves and to carry on living their day-to-day lives. The range of study methodologies and study sites indicates the far-reaching extent of the use of information to self-manage.

2.3.6 How people with T2DM access and make use of nutrition information

The themes arising from the questions about access and use of nutrition information included the impact of having knowledge about a source of information and its use and applications, and the way that accessing and using information sources increased knowledge and skills in managing T2DM.

Knowledge about a source encouraged use and application

The findings from two studies on the use of food labels suggested that knowledge gained from an HCP impacted on participant use. Kessler and Wunderlich (1999) found that although food label use was higher amongst those who have diabetes, an understanding of food labels was higher in those who had seen a diabetes HCP. While Fitzgerald et al. (2008) found that, for those with T2DM, seeing a dietitian encouraged the use of food labels, knowledge in both those with T2DM and those without T2DM was linked to using food labels to choose healthy foods. Although five studies found that food labels were a source of nutrition information for people with T2DM, the findings from these two studies underline the potential challenges in being able to use food labels to manage T2DM and the importance in receiving guidance from an HCP to encourage and facilitate usage of food labels.

Interacting with nutrition information develops knowledge

Several studies found that interaction with nutrition information sources increased knowledge amongst people with T2DM. This appeared to be with sources where active interaction was

encouraged such as in an interactive website and in group education sessions. For example Herrejon et al. (2009), in their evaluation of a newly developed website designed for people with T2DM, found that the interactive aspects of the website were used more frequently and that the use of these with successive attempts led to an improvement in nutritional knowledge. Martins et al. (2014) in their study evaluating the impact of a carbohydrate counting course, found that after having attended a four-hour course on diet and diabetes, one year later, overall understanding improved, however, this was despite ongoing difficulties in comprehending certain aspects of the diet. Watson and DuFourd (1992) also found an improvement in knowledge following attendance at group education sessions, this time in comparison with those who had not had diabetes education. Waller and Tzeng (2011) explored the impact of attending education sessions. They found that knowledge about a specific dietary attribute that may assist in the management of T2DM (in this case glycaemic index) and the ability to apply the newly attained knowledge to their own setting increased following attending an education session where information on the specific dietary attribute was provided.

These findings suggest that knowledge increases with active use of nutrition information sources that have an interactive component such as interactive websites, and group education where active participation is encouraged.

Practical skills

Studies have indicated that information is needed to develop practical skills in order to be able to self-manage (Byrne et al., 2017; Waki et al., 2015). These studies highlight the importance of adapting information into a practical format so that people with T2DM can apply this to their own situations. For example, Byrne et al. (2017) adapted into a practical educational experience the national nutritional guidelines and Waki et al. (2015) included a food log showing portion sizes and nutritional values both of which enabled the participants to apply their experiences to their own daily diet showing an improvement in the diabetes control.

However, studies have also found that not having the information in the form of skills, meant that the information had limited impact on the participants' abilities to apply the information to their own diets and their own social context. (Lawrence et al., 2017; Murrock et al., 2013; Scott, 1997). Murrock et al. (2013) found that although basic advice had been provided by a dietitian and or GP, this did not enable participants to flexibly adapt their diets when eating with family and friends.

Lawrence et al. (2017) found that participants needed, amongst other types of information, information on cooking methods in order to help them manage their T2DM. Scott (1997) found that without practical information that related to the traditional diets participants were not able to apply the advice that they had been given to decisions about what to eat.

The use of information in a practical format improved diabetes control, while the absence of such information prevented participants from being able to apply dietary advice for T2DM to their own setting.

2.3.7 Information experiences of people with T2DM

Lack of satisfaction with nutrition information was a common theme across the included studies and there were just a few studies that recorded positive nutrition information experiences. Common information experiences consistently found across the studies were lack of information, difficulty in understanding the information, the importance of patient-centred information and the complexity of the information.

Satisfaction and trust

Nine studies explored and or reported on the presence or lack of satisfaction with and trust in the nutrition information received by people with T2DM (Ball et al., 2016; Ball et al., 2012; Frandsen & Kristensen, 2002; Lawrence et al., 2017; Matpady et al., 2020; Meyfroidt et al., 2013; Miller et al., 1997; Scott, 1997; Wermeling et al., 2014).

Eight studies explored the satisfaction and trust in the advice received from HCPs (Ball et al., 2016; Ball et al., 2012; Frandsen & Kristensen, 2002; Lawrence et al., 2017; Matpady et al., 2020; Meyfroidt et al., 2013; Scott, 1997; Wermeling et al., 2014). Three studies found that participants were satisfied with the advice. Ball et al. (2012) found that while less than half the participants had received nutrition care from their GP there was a high level of satisfaction with nutrition care received; Meyfroidt et al. (2013) found that advice from the GP and dietitian were felt to be the most valuable and Lawrence et al. (2017) found that advice from the nurse was the most trusted source. However, five of these studies found participants were dissatisfied with the information and advice they received, finding it was not patient centred and that practitioners lack access to appropriate resources and did not understand traditional diets. Ball et al. (2016) found that while seeing a dietitian gave participants more confidence in being able to follow the dietary advice, the

guidance was not often individualised; Frandsen and Kristensen (2002) found that the lack of information led to mistrust and the need to seek information from other sources; while Lawrence et al. (2017) found that participants lacked trust in the advice from HCPs as the advice was constantly changing. Wermeling et al. (2014) found that although the GP was key in providing guidance to people with T2DM on how to manage their diet and diabetes, often this did not take into account their personal context; Matpady et al. (2020) found that advice needed to be tailored to an individual's lifestyle, and Scott (1997) found that HCPs did not have a good understanding of the West Indian diet, which they suggest may be due to lack of resources in enabling them to provide patient-centred advice.

Miller et al. (1997) and Lawrence et al. (2017) explored satisfaction with other information sources. They both identified a lack of trust in the information on food labels, in nutrition claims and information from restaurants. For example Lawrence et al. (2017) found that participants felt that the marketing techniques used in food labelling by the food industry prevented them from being able to use them to make judgements about which foods to eat. Miller et al. (1997) found that their participants also mistrusted the information on food labels due to concerns about marketing. While they understood and trusted the guidance about specific foods from a national heart association, they did not trust the specific claim when it appeared on food packaging.

HCPs may be the most trusted source of information however studies found frequent dissatisfaction in the advice provided with participants needing to seek advice from other sources. Although there is limited research exploring the satisfaction and trust with other sources, the research which was identified in this study relating to food labels indicates there is limited satisfaction with these sources also.

Lack of information

Six studies indicated that nutrition information is either not available, the information delivered is incomplete or there is insufficient time to process the information. Although Ball et al. (2012) found that a significant number of people in their study had received sufficient information, other studies identified a lack of information. For example Albright (1994) found that information was often not given at all, while Ball et al. (2015) found that insufficient time was available to be able to understand and process the information. Lawrence et al. (2017) found that the information was delivered 'piecemeal', Breland et al. (2013) found that information was abstract and both Breland et

al. (2013) and Matpady et al. (2020) found the information was sporadic. Lack of information or incomplete nutrition information appeared to be a common experience in the identified studies.

Complexity and difficulty in understanding the information

Not only was information not delivered but, when it was, studies found that the information given was complicated, overwhelming, conflicting and difficult to understand. For example, both Albright (1994) and Ball et al. (2015) found that participants' experiences of the information delivered by HCPs was that it was overwhelming. However even in scenarios such as where participants had attended group education or received education, participants had difficulty in understanding the dietary advice (Miller et al., 1997). Some studies found that there were particular aspects of the dietary advice that was more difficult to understand. For example, Lawrence et al. (2017) found that participants had difficulty in understanding the differences between different types of carbohydrates including sugars and the concept of glycaemic index. Miller et al. (1997) identified that participants did not understand the concept of percentage energy on food labels (and so ignored this) and also the difference between different fats and different types of carbohydrates.

The findings from these studies suggest that the delivery of nutrition information is challenging and complicated, people with T2DM find it overwhelming and difficult to follow even when they have had advice and education. Indeed three studies found that it was the concept of nutrition advice for people with T2DM itself that was complex. Ball et al. (2012) and Pinto and Braz (2016) found that as nutrition care is complicated this is a challenge for HCPs and people with T2DM alike. Indeed, in order for Byrne et al. (2017) to study the impact of nutrition education on diabetes outcome measures, national guidance needed to be translated to enable application to everyday lives. However, it was not just the complexity of nutrition care that was found in studies as being challenging, it was the automatic, hidden nature of daily food activities that made it difficult for HCPs to deliver nutritional advice. For example Breland et al. (2013) identified that HCPs did not understand people's lives and the decisions that their participants needed to make as food provisioning is 'automatic'.

Patient-centred information

Information delivered by HCPs was found to be directional and did not take into account participant circumstances, for example the food they traditionally eat, or was not in sufficient depth to be able to apply to their own context. HCPs did not understand people's lives and the basis of the decisions

they made about what to eat. However cultural/social context itself can make it challenging to apply nutritional information.

A number of studies identified that the nutrition information that was delivered was not patient centred. For example, Ball et al. (2016) found that interactions with a dietitian tended to be directional and not individualised. Other studies found that HCPs did not understand or take into account participants' contexts. Breland et al. (2013) found that participants felt that HCPs did not understand people's lives and the daily decisions they made about what to eat and the advice was 'generic and vague'; Scott (1997) and Lee et al. (2016) found that participants did not receive the advice that took into account their traditional food preferences; and Murrock et al. (2013) found that the information from HCPs was not geared towards the setting in which their participants lived. Wermeling et al. (2014) found the information did not take into account individual contexts. Whilst their participants recognised the value of their GPs in supporting their diabetes management, they needed the information to be translated so that they could apply it to their everyday lives and they did not find that the GP was able to do this.

Impact of active engagement with information

The active use of information such as in an interactive website (Herrejon et al., 2009) or in group education (Byrne et al., 2017; Martins et al., 2014) appeared to enable participants to apply the information to their own setting. For example, Byrne et al. (2017) found that the impact on diabetes outcome measures following the Healthy Teaching Kitchen course improved after the completion of the self-management education and Martins et al. (2014) found that the practical aspect of the course improved diabetes management despite ongoing difficulties in understanding the carbohydrate counting method taught in their programme. However, Mphwanthe et al. (2021) found that peer support groups where participants were actively providing information to each other was a facilitator in healthy eating. Additionally, Cradock et al. (2021) found, that by engaging participants in their daily food activities through the diary approach, facilitated them in planning food provisioning activities which influenced their ability to follow a healthy diet.

Other studies found that participants were in need of this practical information. For example, Lawrence et al. (2017) found that participants needed information on cooking to help them manage their diabetes; Murrock et al. (2013) found that participants needed individualised help in planning meals so that they could be flexible with what they are with family and friends; and Scott (1997)

found that their participants needed to know how to apply the information they were given so as to incorporate traditional foods in their daily decisions.

2.4 Summary

Twenty-eight studies utilising a range of methodologies, with participants across a wide age range of adults with T2DM from international study sites, recruited from both healthcare and non-healthcare settings were identified. While all studies had a focus on nutrition information activities none used an information behaviour or practice model such as Longo et al. (2010) or Savolainen (2008) to support their research design. This may indicate less developed research in this area and a potential for further research.

Despite the heterogeneity of the studies across age ranges, male and female, recruitment settings, countries (and therefore health systems) using different methodologies, the review identified a number of common themes. While some studies focused on specific ethnic groups and age ranges others did not have these specific foci. Most of the studies originated in the USA, while the remaining studies were from across the world, just one study was set in the UK. This was surprising considering the prevalence of T2DM in the UK.

The review identified experiences and impact as being the two main aspects to nutrition information activities explored in the literature. While the experiences identified were not always positive and factors requiring improvement could be applied to the provision of nutrition information, the identification of nutrition information activities as having an impact on people to be able to self-manage is key in supporting further research in this area.

The smaller number of studies exploring the involvement of dietitians and group education indicate a potential lack of appreciation of dietitians and group education as key sources of nutritional information. While group education was identified in chapter 1 as important for people with T2DM to attend, its relevance as a source of information may have been overlooked by researchers investigating and exploring nutrition information. Although the value of group education is that it is interactive, the very term 'group education' may discourage people who do not enjoy or find it challenging to interact with others in a group setting. Advertising group education as a source of information may encourage more people with T2DM to attend. The term information as opposed to education suggests flexibility and choice to apply to a nutritional situation as the patient sees fit.

There was a frequent satisfaction with nutritional advice provided by HCPs despite the identification that the information was often not being complete and not patient centred. The frequency of the theme of satisfaction and trust versus dissatisfaction, lack of individuality and patient centredness across study settings and methodologies indicates the issue is widespread and not just limited to one country, study setting or system of healthcare. The widespread assumption that any HCP can deliver nutritional advice and the frequent omission to provide information that meets individual needs is worthy of further research.

Three main domains for the sources of information were identified: contact with people, written information and information delivered by the media. However only three studies explored nutrition information for people with T2DM across these main sources. This suggests that there is further scope to research the potential of a wide range of sources in facilitating the self-management of T2DM.

The review has identified that nutrition information may refer to the broad concept of, for example, nutrition care but also to specific aspects of dietary information such as meal planning and food preparation, nutritional value of different foods and information about eating out. The reasons for accessing nutrition information were explored. Participants really wanted to be able to incorporate the advice into their day-to-day lives, that is into their tacit food provisioning activities so that they could eat alongside their families and be able to live their lives. The hidden and taken for granted nature of food provisioning alongside the instinctive process of information activities make exploring the experiences of nutrition information activities for people with T2DM difficult. Pinning down what it is that people with T2DM want to achieve through nutrition information activities is challenging as both information activities and food practices are tacit and mundane; it may be as simple as being able to be 'flexible' so they can still eat the foods they liked but at the same time be able to manage their diabetes (Murrock et al., 2013), that is live their normal lives with their diabetes.

Two-thirds of the studies focused on the impact of nutrition information activities. Nutrition information enabled participants to be able to develop knowledge particularly in settings that encouraged interaction. While some studies identified the development of practical skills a number identified that the lack of this type of information limited the ability to apply information to their own settings. Indeed, many studies identified the shortfall in the provision of nutrition information, it was either lacking, or difficult to understand or incomplete or not patient centred, that is, not adapted to the individuals setting. This negativity about the experiences of nutrition information in

people with T2DM underlines the point made by Ball et al. (2012) and Pinto and Braz (2016) that nutrition information is complex. There are many topics to be discussed and the delivery needs to be able to consider individual needs and to take into account the embodied tacit and mundane nature of food practices. While the provision of nutrition information by dietitians did not always meet with a high degree of satisfaction, they are the only HCPs who are specifically trained to deliver patient-centred nutrition information to people with T2DM. This suggests that further work is needed to equip dietitians with the skills to work with their patients in order to provide patient-centred nutrition information and to train other HCPs in supporting them.

Strengths

The strengths of this review are the use of a systematic approach to study identification, specifically the use of the PRISMA checklist and flow diagram. This enabled the identification of heterogenous relevant studies despite there being limited research in this area. While studies may not have overtly labelled their research as exploring or investigating nutrition information behaviour or practice, studies were included if nutrition information sources were referred to within the studies and that this was a main focus of the study.

Limitations

The limitations of this review are that by taking the approach to only include those studies whose main focus was information, nutrition or diet and T2DM may have led to omission of studies that could have contributed to the review. While the search terms 'passive', 'active' 'proactive' and 'avoidance' were specifically included in order to enhance the potential identification of studies relating to information activity (behaviour/practice), they may have also led to the exclusion of relevant studies that could have contributed to the review. The heterogeneity of the studies prevented a quantitative assessment of the findings and almost all of the studies had quality issues.

This systematic narrative review has identified that nutrition information is key to enabling people with T2DM to be able to live their daily lives. It has however also identified the complex and tacit nature of nutrition information for people with T2DM. This contrasts with the current view that diet for T2DM is simply about eating a healthy diet⁵. It may be the case that the topics and advice are very similar to that featuring in a healthy diet, however, being diagnosed with a disease that can

⁵ For example, the NHS explains on their website for people with T2DM that 'a healthy diet and keeping active will help you manage your blood sugar level' NHS (no date) Food and keeping active: Type 2 diabetes.

Retrieved 2nd May 2021 from https://www.nhs.uk/conditions/type-2-diabetes/food-and-keeping-active/

lead to life-changing and life-threatening complications alters the approach to incorporating the information. While the studies identified a wide range of sources of information and topics, no individual study sought to identify or address the impact of needing to utilise a wide range of sources and the complex and tacit nature of nutritional information overall. Although studies identified the complexity of nutrition information and the importance of individual information, no study appeared to acknowledge the complex and embodied nature of food practices and that information practice is instinctive. Also, while the food provisioning processes, and the development of practical skills were identified, no study identified the concept of information practice in exploring the way that people with T2DM access and use nutrition information in order to live with their T2DM. The aspects of the tacit nature of nutrition information access and use in order to self-manage T2DM is worthy of further study.

3 Chapter 3: Empirical research study - Methodology

3.1 Introduction

In this chapter the methodology and methods adopted and developed for the empirical research study are explained and justified. The findings of the systematic review suggested that further research is needed in order to investigate the nutrition information practices undertaken by people with T2DM. Specifically a study is needed which can explore the practices incorporating the wide range of sources used by people with T2DM alongside the complex, hidden and tacit nature of nutrition information practices in people with T2DM.

As identified in the systematic review, while studies have explored nutrition information behaviour/practice, few have identified the instinctive, embodied and hidden nature of information practice as explored in Chapter 1 (Case & Given, 2016, p. 68; Cox, 2012; Fischler, 1988; Lloyd, 2010; Merleau-Ponty, 1962, p. 25; Savolainen, 2008; Spink, 2010, p. xii; Wills, 2012). However, the study of information activities especially those relating to nutrition in the presence of a long-term condition can be challenging because information behaviour, food behaviour and activities relating to self-management are everyday activities that are tacit and difficult to recall. Information activity is a 'core human capacity', and the need for information is an everyday activity (Spink, 2010, p. xii). Similarly, food and eating practices are everyday tacit activities (Wills, 2012). For people with T2DM, taking care of what is eaten is an everyday self-management activity requiring multiple, complex and interlinked considerations, decisions and actions throughout the day and these may not be easy to recall (Johnson & Bytheway, 2001). Therefore, when studying people with a long-term condition such as T2DM utilising methods that are reliant upon participant memory in order to capture practices that are tacit and complex may not fully reveal the activities being studied.

Thus, the methods identified in this study will need to take account of the hidden nature of information practice in order to be able to answer the research questions. As there is limited research in this area an exploratory approach using qualitative methods was selected.

3.2 Qualitative methodology

This study has adopted a broadly social constructionist ontological and epistemological approach (Barbour, 2014, p. 43; Berger & Luckmann, 1967; Green & Thorogood, 2018, p. 44). That is, the

researcher has rejected the notion of a single reality (ontology) and adopted the idea that reality is based on social construction through interaction (epistemology).

Social constructionism challenges individualism and personality and sees the world and knowledge as being socially constructed by our society through our daily human interactions (Burr, 2015, p. 4). Indeed, Burr (2015) suggests that social constructionism would question basic assumed concepts such as humans are either men or women, and instead suggests that social constructionism would say that our categorisation of men and women is culturally specific. The ontology is not without its problems in that there is no space for the concept of personality or embodied experiences and there is often a struggle between how new knowledge is created, is it through society influencing individuals or through individuals influencing society (Burr, 2015, p. 207)? Berger and Luckmann (1967) suggest that this is not an issue since we should see society and humans as one and so when we say that knowledge is created by society we are acknowledging the individual component in the creation of knowledge (Berger & Luckmann, 1967, p. 17). Consistent with social constructionism the approach to analysis adopted for this study is that of interpretivism, using thematic analysis to interpret the data collected (Braun & Clarke, 2013, p. 30). The underpinning theoretical framework used is that of information practice (Savolainen, 2008) within the discipline of practice theory (Schatzki, 2001a; Shove et al., 2012).

3.3 Identification of the methods used

Diaries are known for their utility in research exploring everyday and tacit behaviours as they enable 'first hand recording' of such behaviours (Plummer, 2003, p. 1) and when used alongside interviews help to explain how people 'make sense of their lives' (Plummer, 2003, p. 3). The diary-interview approach has been used to explore food use (Dickinson, 2003) and health information behaviour amongst older people (Hurst, 2016). The use of a food diary followed by a dietetic consultation features regularly in every day dietetic practice with people with T2DM where patients are advised to keep a record of their food intake for a short period of time (usually 3 days). The record is used as a reminder to the patient and helps the dietitian structure discussions during the consultation (Deakin, 2016, p. 131). However, there is limited research that uses a qualitative diary alongside an interview when exploring nutrition information activities.

Researchers have proposed using the solicited diary in order to overcome issues with memory and recall (Hyers, 2018, p. 63; Johnson & Bytheway, 2001; Plummer, 2001, p. 51) and the tacit and taken for granted nature of food related practices and behaviours. For example, MacDonald, Murphy, and

Elliott (2018) in their study of family food practices asked families to keep a diary of these practices; Bava, Jaeger, and Park (2008) when researching food provisioning, asked women to keep a diary of time and food consumption; and Dickinson (2003) asked her participants to keep a food consumption diary in order to explore the impact of food on the everyday lives of older people; Hurst (2016) asked her participants to keep a diary of health information they came across and used. However, there is limited research utilising the diary approach to explore nutrition information activities especially amongst people who have a long-term condition such as T2DM. Diaries may reveal more than a definitive account of individuals' actual behaviour and therefore may not be diaries as such but rather 'essays about peoples' lives' (Meth, 2003, p. 199), therefore this fits well with the tacit and hidden nature of food and information practices. Furthermore Bartlett and Milligan (2015, p. 8) explain that the diary goes beyond ensuring that activities are recorded accurately. If an unstructured approach is utilised the diary method can elicit data that is not only 'naturalistic' but also provides an understanding that is centred in the participant's day-to-day experience (Bartlett & Milligan, 2015, pp. 15,21). Diaries can help to provide context and, particularly when handwritten, can sensitise participants to tacit and hidden activities and thoughts (Cradock et al., 2021). Therefore, an unstructured handwritten approach could facilitate the identification of food and information activities that participants may not be aware of.

Diaries are often used as a 'precursor or adjunct' to other methods (Bartlett & Milligan, 2015, p. 25). For example, in the seminal study by Zimmerman and Wieder (1977) diaries were used where direct observation would affect the everyday behaviour that was the subject of study and were followed up with in-depth interviews to confirm diary entries. However, rather than using interviews to corroborate diary entries, other researchers have used follow-up qualitative interviews to gain a deeper understanding of diary entries (Bava et al., 2008; Graffigna, Barello, Libreri, & Bosio, 2014; MacDonald et al., 2018).

Similarly, interviews on their own may not reveal experiences that are considered 'everyday' and taken for granted since participants might deem these unworthy of mentioning or they are unaware as these behaviours are tacit. Indeed, the use of the follow-up interview to a diary has been found to enhance both the diary data as well as the interview data (Brownlie, 2018; Hurst, 2016; Spowart & Nairn, 2014). This methodological approach is commonly referred to as the 'diary-interview' method (Milligan, Bingley, & Gatrell, 2005) reflecting the synergistic effect of combining the two methods in one study.

As both food and information activities are considered routine (Spink, 2010; Wills, 2012) the diary-interview method is an appropriate method to explore this topic further. The aim of the next section is to outline the development of the diary-interview method.

3.4 Development of the diary-interview method

A review of literature relating to diary collection methods identified a number of methodological aspects reported to influence data collection. These included the diary format, completion period, and the amount of guidance provided (Braun & Clarke, 2013, p. 30). Diary studies vary in length depending on the focus of the study. For example, McKenzie (2003), when exploring information practices amongst women pregnant with twins, asked participants to keep a diary for one week, and Keleher and Verrinder (2003) undertook a 3 month health diary with their participants in rural Australia. However, researchers have cautioned against the diary completion period being too short or too long. Corti (1993) warns against short diary completion periods as participants may record more information or events than would reflect their normal practice referring to this as 'first day effects'. Johnson and Bytheway (2001) noted that diary entries of their participants reduced after one week referring to this as 'respondent fatigue'. Sillence, Briggs, Harris, and Fishwick (2007) who asked participants to keep an internet information diary to log the sources of information they accessed over a six-month period found diary completion to be sparse. Keleher and Verrinder (2003) suggest that the most common diary period is 4 weeks, however, in their study in order to ensure that records relating to contact with HCPs were included in their health diary, they extended their diary period to 3 months.

Researchers have given attention to the format of the diary in order to enable participants to effectively note their entries (Bartlett, 2012; Griffiths et al., 2007), for example audio, photographic and paper diaries (Bartlett, 2012; Hinsliff-Smith & Spencer, 2016) and typed or handwritten diaries (Hyers, 2018, p. 87).

Diary format may also impact on data collection. For example, a format that consists of a complex table requiring a range of different data to be entered may overwhelm participants such that they feel unable to make diary entries (Alaszewski, 2006, p. 78). Some structure may be needed in order to collect the data required to answer a study's research questions (Johnson & Bytheway, 2001; Zimmerman & Wieder, 1977). However, a more unstructured approach (supported by simple introductory guidance) has been found by Hinsliff-Smith and Spencer (2016) to capture feelings and

experiences about breast feeding that were not influenced by what the researcher wants to know. Bartlett and Milligan (2015, p. 15) suggest that using an unstructured format (coupled with guidance on the research topic) may make diarists feel empowered to make entries. Although, when using an unstructured approach researchers suggest some form of template or guidance is needed to encourage diary entries (Hyers, 2018, p. 85; Spowart & Nairn, 2014, p. 331).

In order to enhance data collection researchers have given participants the option of using alternative methods other than the traditional written diary. For example, MacDonald et al. (2018) and Hislop, Arber, Meadows, and Venn (2005) utilised an audio diary where participants were unable to write or preferred to use this option. Comparing the accessibility of using audio diaries versus written diaries has identified conflicting results. For example, Brownlie (2018), in order to enhance data collection relating to 'taken for granted' practices had offered a range of tools including, written, drawn, texting, audio and camera diaries, found that the majority provided their diary data in written format. They recruited participants with ages ranging from18 to 89 years and from backgrounds aiming for maximum diversity, however, they found that the majority of participants provided their diary data in written format. While Bernays, Rhodes, and Jankovic Terzic (2014) exploring the role of hope in people living with HIV, found that the audio diary produced richer data than was recorded in written diaries.

O'Connell (2013) suggested the use of visual techniques such as scrapbooks and drawings may encourage a greater engagement in the data collection process. Wills, Dickinson, Meah, and Short (2016) found this approach enabled an understanding of kitchen practices from their participants' own viewpoint. Indeed Power (2003) proposed that incorporating visual techniques supports the capture of data relating to embodied and tacit experiences as these may be difficult to put into words.

Building good relationships between the researcher and diarist is important for both extended and shorter diary periods (Bartlett & Milligan, 2015, p. 39; Keleher & Verrinder, 2003; McKenzie, 2003; Milligan et al., 2005). For example McKenzie (2003) telephoned each of the participants twice in their week-long study and Keleher and Verrinder (2003) also found that regular contact of twice per week promoted engagement in their 3 month long study. However, keeping in touch has not always resulted in diary completion. For example, Sillence et al. (2007) reported that despite regular reminders only ten out of the 15 participants completed diaries.

The diary approach gives an indication as to the subject being explored at that moment in time when it is completed by a participant (Alaszewski, 2006, p. 1). When research questions aim to understand a phenomenon that is beyond that individual point in time, enabling reflection on the diary entries, enhancing involvement in the research process (Brennan et al., 2014; Elliott, 1997; Hurst, 2016; Spowart & Nairn, 2014), interviews are often undertaken alongside diaries.

The format of the interview element within the diary-interview method is also key to this approach and will depend upon the research paradigm utilised by the researcher (Brinkmann & Kvale, 2015, p. 51). Zimmerman and Wieder (1977) saw their diarists as ethnographers of their own behaviours and utilised the interview in order to confirm the accuracy of diary entries. While MacDonald et al. (2018, p. 5) utilised a phenomenological approach where participants were able to expand further on their diary entries during the interviews. Hurst (2016) adopted a constructivist grounded theory approach to her diary-interview method in order to understand the health information behaviour of older people. In contrast, in the post-structuralist approach to research used by Spowart and Nairn (2014), diaries were used as starting points for the participant-led interviews. This enabled participant reflection and the creation of new knowledge regarding the lives of their participants. In this current study a broadly social constructionist approach (Barbour, 2014, p. 43; Berger & Luckmann, 1967; Green & Thorogood, 2018, p. 44) was adopted. Therefore, interviews were used flexibly to explore the day-to-day information experiences recorded in the diaries as well as using these as a starting point to understand nutrition information practice within the context of people's lives.

Refinement of the method

Qualitative research methodologists recommend piloting actively followed by discussions with the research team when refining methods (Seidman, 2013). The pilot enables a review of the utility of the chosen method to answer the research questions; practical aspects relating to the implementation of the method and an assessment of the skills of the researcher in the application of the method (Alaszewski, 2006; Bell & Waters, 2014, p. 199; Sampson, 2004; Seidman, 2013; Van Teijlingen & Hundley, 2001).

A process of informal piloting was implemented in the development of this study. The aim of the pilot work was to consider the practical aspects relating to the diary and interview process. The researcher needed to find out if the concept worked. Would people be able to record information

they came across, would the information experiences be so embodied and instinctive that they would not realise to record them? When undertaking the interviews would participants talk naturally about nutrition information? If the process was successful, the researcher knew that they would need to find out if the diary instructions were clear enough to enable participants to be able to follow the instructions and record nutrition information they came across. The researcher also needed to explore the format of the interview, the questions, the recordings, the process of undertaking an interview.

The pilot work also provided some further insight into ethical aspects of the study, how should the interviews with participants be undertaken, how should confidentiality be protected. This was in addition to the pilot work also giving the supervisory team and the lay groups involved in the pilot stage an opportunity to discuss methods and to suggest further adaptations.

First pilot phase

The initial imperative in undertaking pilot work was to consider the practical aspects relating to the diary. The aim of the pilot was to explore participant experiences of the research process in order to test and inform the final method. An unstructured approach to diary format was selected which was followed by an interview aiming to clarify the diary entries and explore further nutrition information experiences.

The first draft of the unstructured diary format and the semi-structured interview process was piloted with a married couple, the husband in the partnership having T2DM and his wife, who was involved in the household provision of food. Each participant was given an A5 hard backed note book (for portability and to ensure that the diary had sufficient pages to last for the time period of data collection (Thomas, 2015)), along with information about the study. They were asked to record their thoughts and views each time they read, saw, listened to or were told something that related to the nutritional management of T2DM. They completed the diary for three days. A list of potential sources as identified by Meyfroidt et al. (2013) and guidance on what to record were given at the front of the diary, leaving the remaining diary pages blank.

The diary was followed up one month later with a joint interview in the participants' home (at the convenience of, and as agreed with, the pilot participants) about the process and the pilot participants' experiences of nutrition information. A semi-structured approach to the interviews

exploring specific diary entries was used. A basic topic guide that could be adapted following analysis of diary entries was developed that included the research questions of use and acquisition of nutrition information. Utilising guidance from Brinkmann and Kvale (2015, p. 156) on the format of topic guides, broad questions were followed up with further probing questions, where the researcher asked about aspects of a subject which the participant may not have mentioned and which were based on the preliminary analysis of the diaries. Following the interview field notes were made reflecting on the diary and interview process.

As found by Kenten (2010), in the current pilot, the content of the two completed diaries were very different. The diary kept by the husband with T2DM was detailed and related to information found on food labels whilst the diary from his wife, who was the household food manager and who did not have T2DM, related to decisions made about what food to prepare on the basis of information she read. The husband was interested in learning facts about food and made records throughout the day. However, his wife made records that related to making sure that the 'right' food was produced and that it tasted good. Unlike her husband she completed her diary at the end of each day. The field notes recorded the value in interviewing the couple together as 'there was some useful interaction between the participants, sharing ideas as to what they do and showing their different approaches' to keeping the diary.

The pilot study identified the utility of the method in yielding experiences of nutrition information, the value of the semi-structured interview to clarify diary entries and the possible processes for diary completion. This included keeping the diary with them and completing as they go or at the end of the day and how engaged they were in the process and the concept of nutrition information. However, further refinement of the participant information in the form of a leaflet about the study, the guidance given to participants about the diary and the wording of the interview questions was needed.

Public involvement in the research process

In order to further ensure that the method would be as effective as possible and to review appropriate recruitment strategies, guidance was sought from two lay groups of people who had T2DM. These included members of the University's public involvement in research group (PIRG), convened by the author's Research Centre, who either had T2DM or who cared for someone with T2DM, and members of a UK diabetes charity local support group. The PIRG were uncertain as to

whether participants would make diary entries, suggesting a focus group approach would be a more effective method, while the diabetes support group felt that the diary approach was feasible, suggesting a four-week diary completion period was likely to be acceptable.

The PIRG suggested that if a diary method were used, instructions should be simple, that guidance on how to complete the diary on a daily basis would be helpful. They advised on simplification of the instructions, on alternative methods for participants to communicate with the author during the diary keeping phase (such as telephoning or emailing) and suggested that participants keep a sample of the information they accessed or could take a photograph of it. Advice was given by the lay groups regarding the order of interview questions, suggesting the collection of personal data at the end rather than at the start of the interview. The groups also suggested a more informal style to the participant information sheet including answers to additional potential participant queries and simplification of the consent form.

Second pilot phase

To test the efficacy of the lay guidance, the second pilot involved two couples, one member in each couple having T2DM and the other member having involvement in the household provision of food. Each pilot participant was given their own diary which included instructions on the inside of the front cover and narrative prompts at the top of the first side of each of the 28 double pages. They were also sent email reminders across the four-week period. At the end of the diary period the diaries were collected and a date for the follow-up interview was arranged. Couple one chose to keep a joint diary while couple two chose to keep two separate diaries. Each diary was analysed with aspects needing exploration highlighted on the topic guide. Each couple was interviewed in their own homes; couple one (joint diary) chose to be interviewed jointly, while couple two (two individual diaries) chose to be interviewed separately.

Pilot participants reported that the email reminders encouraged them to make diary entries. They also explained that initially they were concerned that they would not be able to make any entries as sources of nutrition information did not seem that relevant to them. However, when keeping the diary, they become more aware of nutrition information around them and were reminded of information they had used in the past.

The pilots confirmed the practical aspects of the diary and the clarity of the diary instructions. The format was easy to follow and they suggested the inclusion of a glue stick with the diary to facilitate the saving of examples of nutrition information such as food labels. Field notes recorded their comments about the process for diary completion. They explained that they found the experience 'unnatural' as they said they would not normally have accessed any information and not taken any notice of information having accessed nutritional information in the past. During the diary period however they looked for relevant information to include such as food labels, information in diabetes publications and websites and they also analysed the nutritional value of the foods they ate. They commented that the process identified what information may be available to people with T2DM. The notes also indicated that should couples be recruited, giving them the option of completing a single diary or separate diaries and interviewing together or separately should be offered as this would meet participants preferences and facilitate the collection of rich data. This aspect was further discussed with the supervisory team and PIRG with the agreement that couples that were recruited would be given the option of completing a joint or individual diary and of being interviewed together or separately.

3.5 The diary-interview study

In this section the details of the diary and interview process is given. The final diary format is detailed. The way that the diaries were completed by the participants is explored. The adaptation of the topic guide for each individual participant and the interview settings are explained. The process for sampling is described and the method used for data analysis is detailed. Finally, the chapter finishes with a recounting of the ethical issues encountered during the study.

The diaries

The diary format was further developed for the study, based on the findings from the pilot phases. The narrative prompts (see figure 2) and the diary instructions were simplified (see figure 3), a diary pack was developed, and regular email reminders were standardised (appendix 6). The diary pack consisted of an A4 sized plastic wallet. This contained the participant information leaflet and consent form, hard backed A5 notebook with lined pages, pencils, coloured pens, a disposable camera and a glue stick (see figure 4 Diary Pack).

Figure 2 Diary daily narrative prompt

Day.....Date....

Have you come across any information about what to eat today? Record for each:

- The type and source and summary
- Were you able to use the information
- Did you search for it or just saw it?

Figure 3 Diary instructions

DayMonday......Date 2nd February

Have you come across any information about what to eat today? Record for each piece of information:

- the type and source and summary of the information
- were you able to use the information?
- did you search for the information or saw it?

How should I make a record?



Use the diaryor



call or



email researcher



Save a copy or glue into diary or



take a photo

Examples

Breakfast: Breakfast cereal label; has less sugar than others I usually have. I have photographed the label.

During day: Radio programme- sugar is worse than fat in the diet. Is this true?

Evening: Chicken casserole recipe in paper (saved a copy).

Nutrition Information Type 2 Diabetes Researcher: Jane McClinchy PhD Student

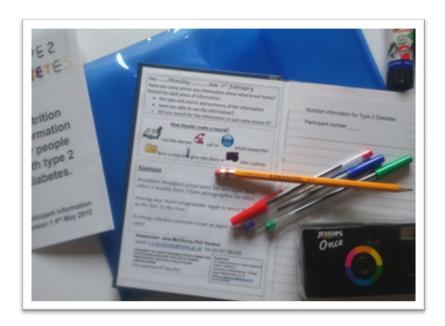
email: Tel:

UNIVERSITY OF HERTFORDSHIRE ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS UH ECDA Protocol number aLMS/PG/UH/00099 (1)

Diary paperwork 7th Sept 2015

Supervisor

Figure 4 Diary pack



Diary process

The diary completion period was 4 weeks in duration. All participants completed their own diary and were interviewed by the author individually apart from one couple, both with T2DM, who completed a joint diary and chose to be interviewed together. After 4 weeks participants were informed by email that the diary period had come to an end. Some responded in surprise that the diary period was over so quickly, one participant, although acknowledging the end point, continued to record diary entries until the diary was collected and one participant said that they would like to continue the process on an ongoing basis. Diaries were collected in person from all participants (apart from one which was returned by post). At this point arrangements were made for the interview date.

Diary entries

As identified by other researchers (for example Kenten (2010)) and during the pilot study, participants made different types of entries in their diaries. For example, Isobel provided extensive text on her food as well as her information activities, while Christopher provided a daily log of his information activities. A typical diary entry was 'No new info, beginning to feel guilty that I am not aware enough of my food intake content'. They used their diaries in different ways and supplied their sources of information in different formats. For example, in addition to the diary, William supplied a large collection of newspaper cuttings, Andrew presented his food labels in a separate A3 plastic presentation folder and Edward supplied typed details of the books he had read in an A4 presentation folder.

Some participants included in-depth analysis of the food labels of the food they had consumed (Andrew, Isobel, Susan). Others focussed on nutrition information they had read in books (Edward); the nutritional value of the food they had consumed (Penelope); what they are each day (William); and their thoughts and feelings about being newly diagnosed with diabetes (Frances and Jennifer). For example, Frances described her diary as being a record of her experiences, as someone newly diagnosed with diabetes, of having to make decisions about what to eat and the effect it had on her blood sugars:

And it was just a thought process of what am I eating, what is the impact it's having, am I doing right, is it wrong, is it good (Frances).

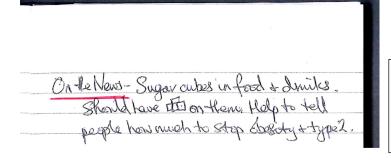
Some participants included samples of food labels while others included an explanation of their view about the layout and clarity of the food label itself, why they had chosen to eat the food, or an opinion as to the nutritional value of the product. For example, Susan was concerned about the amount of sugar in crackers. She included in her diary labels from the packets of those she had looked at and analysed and gave her opinion regarding their sugar content.

Figure 5 Susan's diary: Analysis of sugar values

Day	
······································	
Ingredients Wheat Flour, (Wheat Flour, Suinflower Oil, Five Grails Blend, Acid), Wholewheat Flour, Sunflower Oil, Five Grails Blend, Sugar, Malled Barley Extract, Salt, Raising Agents (Ammonium Bicarbonate, Sodium Bicarbonate), Onion Powder. Five Grain Blend contains: Brown Rice Flakes, Rye Flakes, Wheat Grits, Millet, Flax Seeds. W Allergy advice For allergens, including cereals containing gluten, see ingredients in bold.	<u>Tesco</u> <u>Multigrain</u> <u>Crackers</u>
V Suitable for vegetarians	
Nutrition	
Typical values 100g contains (30g) contain (81* for an average adult 2006 kg and 2006 kg a	
1 felt that 1.19 of sugar per 6 crackers was a good! choice to make	I felt that 1.1g of sugar per 6 crackers was a good choice to make.
1-looked at Oatrakes which are a rather dry afternative	I looked at oatcakes which are a rather dry alternative.
Susan diary facsimile	Susan diary transcription

A number of participants embellished their entries with drawings in order to explain what they had discovered. For example, see below a section from Ruth's diary where she has embellished her comment about the need for images of sugar cubes on food and drink packaging indicating the amount of sugar the item contains in order to help people understand how much sugar is in a particular item:

Figure 6 Ruth's diary: Image of sugar cubes



On the News- Sugar cubes in food and drinks.

Should have an on them. Help to tell people how much to stop obesity and type 2

Ruth diary facsimile

Ruth diary transcription

Participants also showed their engagement in the process by demonstrating ownership of the diary and by giving the researcher messages. For example, Theresa wrote on the front of her diary 'My little book, eat little and often, smile and the whole world smiles with you', on the back she pasted a picture of some daffodils and on the last day of data collection she left the researcher a message hoping that she would enjoy the diary.

Figure 7 Theresa's diary: Front and back cover and message to researcher



Theresa diary facsimile front cover

Theresa diary facsimile back cover

Last day writing in my little book, Hope you Enjoye it.

Theresa diary facsimile note on last page of diary

Last day writing in my little book, Hope you Enjoy it.

.....Thank you

Theresa diary transcription of note on last page of diary

Ruth wrote in the front of her diary that the process had been a useful one in helping her to manage her T2DM and a reminder of the changes she had made.

Figure 8 Ruth's diary: Front page entry

This has been a really good exercise
for me to wide things down as a
good way of monitoring my food rexercise.
Its also a good reference for how far
The come in the last year.

This has been a really good exercise for me to write things down as a good way of monitoring my food & exercise. It's also a good reference far how far I've come in the last year.

Ruth diary facsimile

Ruth diary transcription

How participants made sure they completed their diaries

Participants explained that diaries were kept somewhere prominent such as by the television, on a table, or in a pocket to be readily available to complete. An alternative method that assisted making diary entries was the use of 'scraps of paper or envelopes' where notes had been made. In this quote Ruth describes how initially she kept forgetting to make diary entries, but as she makes notes of what she eats she periodically gathered these notes and wrote them up in the diary:

Yeah, when I first started it I kept forgetting to write anything down, but then as I said I do write things down, so there were random bits of paper in my house. I'd put down, like, what I ate, and I left it somewhere, and then I'd go, 'Oh, haven't written anything in for a couple of days, I must write that in!' So I'd then get the scraps and bits of paper, put them together, and then write them up properly. (Ruth).

Participants likened the nutrition information diary to a food diary (Deakin, 2016, p. 131) which many of them were experienced in keeping and which some were keeping concurrently. This familiarity made the process easier for them, but also because it did not need to be completed every day this made the task less burdensome. For example, Victoria explains how initially she thought that she needed to include everything she ate in the diary but following the emails from the researcher she realised that she did not have to include everything that she ate, making it easier at a busy time for her:

First thing I thought everything had to be put in it, everything, and then you said, 'No, no, it doesn't', so that took a lot of things off. (Victoria)

Participants commented that they did not come across nutrition information on a daily basis and so selected specific days when they would complete the diary such as a shopping day or days when they were likely to have more time. While others noted how 'once the diary was underway' (Naomi) they were more aware as to possible entries that could be made.

The impact of keeping a diary on nutrition information activities

This section refers to discussions with participants and diary entries indicating that the process of taking part in the study had impacted on their behaviour in managing their diabetes.

All participants engaged with the process of keeping the diary, however, a number of participants appeared to suggest that the process of keeping a diary had impacted on their information activities in a beneficial way and in a way which they knew they needed to in order to maintain their health. The process encouraged them to start looking at nutrition information and keeping information they came across as a reference to look at later. They also spoke about how they had used the information they came across to make decisions but also as a reminder as to the changes they had made. For example, Edward comments on how he has changed what he eats for the better as a result of the process:

But I found the whole process useful anyway, because it started to make me think: 'yes, I have changed my diet this week. I've started eating that which I wouldn't have eaten before' and I would just do that as a matter of course previously and not think about it really and what it did it's made you stop and think: 'why am I doing that? What do I expect to achieve from making that change?' (Edward)

The interviews

The interview topic guide incorporated minor amendments informed by the second pilot and consisted of four main areas:

- Diary entries (i.e. regular sources, unusual sources, potential sources that were not recorded in the diary and anything that was not clear)
- Diary process
- Views and experiences of nutrition information in general

 Suggestions for improvement in how nutrition information is made available to people with T2DM

Following a review of each diary collected the probing questions within the guide were individualised for each participant, informed by the content of the diary. Diaries were reviewed for anything that was unclear, for any potential sources of nutrition information that were not mentioned but that had been found to be common sources from previous research (Meyfroidt et al., 2013) and for samples of nutrition information that had been provided by participants. Example probing questions included regular and unusual sources that had been recorded in the diary and any potential sources (that had been identified by other researchers) but that were absent from the diary. Also probing questions relating to how the source was obtained (i.e. how did the participant come across the information, did they actively search for it or did they come across it by chance) and the potential value of the source were included. For example, where newspaper sources were referred to or included in the diary, participants were asked during the interview whether these had been found 'by chance' or had been actively searched for.

Participants who said they used the internet were asked about search methods and key words used where internet sources were referred to. Figure 9 shows an example of the additional questions that were added to one participant's topic guide following a review of their completed diary.

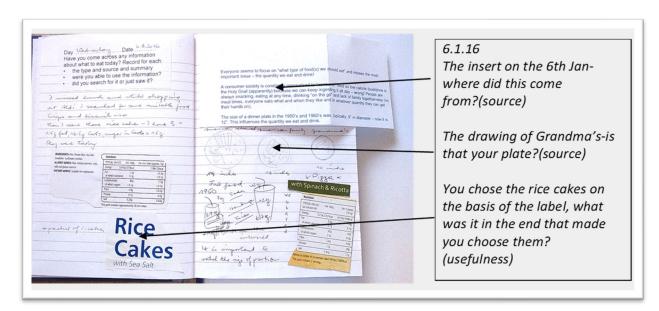


Figure 9 Illustrating how the individualised topic guide linked with one participant's diary

Interviews were planned to be scheduled approximately two weeks after diary collection to enable review of the diary and preparation of the topic guide. When arranging interviews it became

apparent that for some participants taking part in an interview in their own home was not convenient for them (Braun & Clarke, 2013, p. 91). Ethics approval was obtained for this amendment to the protocol enabling a choice of location to participants being offered to participants such as their own home, work or a convenient quiet cafe. The University 'lone working policy' was in place for situations where participants preferred to be interviewed in their own home. At the end of the interview, demographic and personal data that is known to have an impact on information behaviour (Johnson & Case, 2012, p. 5; St. Jean, 2012) was collected in order to be able to understand and describe the study participants. These were age, length of time since diagnosis and diabetes medications.

Interview arrangements

Eight interviews were undertaken in participants' own homes in a room of their choice, one interview was conducted in the participant's workplace and eleven interviews were conducted in cafes in towns that were convenient for the participants. Interviews were held between one and 21 weeks after diary return. As participants did not necessarily start the diary straight away and were not always certain of their future commitments, they preferred to wait until the end of the diary period to set the interview date.

Attempts were made to plan interviews in advance with the first few participants but either delays in starting or completion, or changes in availability meant that these attempts were impractical. The aim was to conduct the interview two weeks after collection. However, in practice this was longer, the average being seven weeks. Reasons for the delay beyond four weeks (n=10) were due to the following reasons: Participants were unwell (n=2), out of the country (n=3), work commitments (n=3) or family commitments (n=2 . To reduce the potential impact of the time between the diary process and the interview, the interview process began with giving the diary to the participants and going through the diary with them.

While undertaking interviews in participant's own homes would appear to initially offer the opportunity for a confidential conversation in a participant's own setting where food provisioning was undertaken this assumption did not always play out. For example, the interview with one participant in the cafe was more relaxed than the initial meeting to explain the study held in her own

home. A number of participants preferred the cafe option as this meant that they were able to incorporate the interview alongside other activities such as food-shopping or work. Oscar explained he was having building work done and so would not be able to meet me in his own home. From the conversation with one participant who was a support group leader it became clear that she wanted to buy me coffee so she could ask me to talk to the diabetes support group she ran. However, assumptions that cafes would be quiet because there were not many people in them were often incorrect as quiet spaces would be filled by new customers and background music would be turned on. Interviews in participants' homes also had their issues. For example, one participant held the interview in their front room with their husband who often also gave answers to the questions from his perspective (these were not analysed) and a dog who barked loudly. The interjections from the husband and dog did not appear to influence the participant, indeed it seemed to set them at ease, especially when their cat also arrived to take part. To ensure there was potential for transcription the recording level was checked at the start of the interview.

3.6 Sampling and recruitment

Inclusion criteria for the study were that participants should either have a diagnosis of T2DM or be involved in the household provision of food for someone with T2DM. A lower age limit of 18 was set and the criteria excluded vulnerable adults who lacked capacity to undertake their own care. The research does not focus on children as they are less likely to have T2DM.

Diabetes UK is the leading charity for people with diabetes in the UK and helps to run support groups for its members. These support groups were selected as potential sources for recruitment utilising the snowball approach to sampling and the use of 'pre-existing relationships' (Lofland, Snow, Anderson, & Lofland, 2006, p. 43). Support groups were identified through the Diabetes UK website with support from the Diabetes UK Volunteer Manager. The chairperson was emailed with details of the study enquiring if the researcher could talk to their group about the study with a view to potential recruitment. Later emails also included the offer of a talk on diet and diabetes. One support group leader also kept in touch with members via email and a newsletter. In this case permission was obtained from the support group leader to include a request within the newsletter. The researcher arranged to meet with local groups and took a sample pack and anonymised pilot diaries to the meeting to help potential participants visualise themselves being able to complete the diary (Plummer, 2001, p. 138). Most of the meetings with the support groups were accompanied by a talk on diet and diabetes given by the researcher. Also, participants were recruited by word of mouth from the researcher's workplace.

The majority of participants (75%) were recruited following talks on diet and diabetes given by the researcher (a dietitian) to diabetes support groups. Overall, nine meetings with talks on diet and diabetes with support groups were held across two counties in the east of England. Fifteen participants chose to take part in the study as a result of attending these meetings. Four participants were recruited as a result of the advert in the Diabetes UK support group newsletter and one participant was recruited via word of mouth. None of the participants were known to the researcher in her previous role as a community dietitian or in her current role as a lecturer in dietetics prior to the start of the study. The impact of the researcher being a dietitian and having recruited participants through support groups was recorded in field notes. For example, field notes from one session noted that the audience (n=10) appeared enthusiastic about the project and from another (n=30) the notes recorded that there were a lot of questions for the researcher during the diabetes and diet session. Only two participants (of the 15 recruited in this way) referred to these sessions during the interviews; Theresa recalled that the researcher had spoken to the support group that she attended; and Isobel commented in her interview that she had been interested in what the researcher was going to say in the talk to the support group that she facilitated. While there appears to be no overt impact of the researcher being a dietitian on the recruitment process, it may have impacted on the diary completion as some participants found the diary similar to a food diary that they were completing alongside or had completed in the past.

3.7 Data analysis

The approach to analysis for both the diaries and the interviews was an iterative inductive process incorporating thematic analysis (Braun & Clarke, 2006) and a process of comparing themes with original data sources and with other themes. This method is flexible in that it can be applied to a range of methodologies. The method also allows for the identification of confirming and disconfirming instances of a code (Silverman, 2006, p. 297). However while thematic analysis is considered to lie 'at the root of all qualitative data analysis' (Barbour, 2014, p. 272) in order to play to its strength a theoretical framework is needed (Braun & Clarke, 2013, p. 178). In this study the two theoretical frameworks of practice theory and information practice were used to guide the analytical process.

Once the data had been collected pseudonyms were allocated to each participant. The diaries were scanned into PDF format with sections that referred to individual towns or names being redacted to maintain confidentiality. The diaries were then transcribed verbatim by the researcher into MS Word

documents. The interviews were transcribed verbatim by a professional transcriber for efficiency. Following the initial transcription, the texts were checked several times to ensure words had been translated into as near as possible text using the notation 'unclear' if words were inaudible. Field notes kept during the interviews and made after the interviews were used to assist with this process.

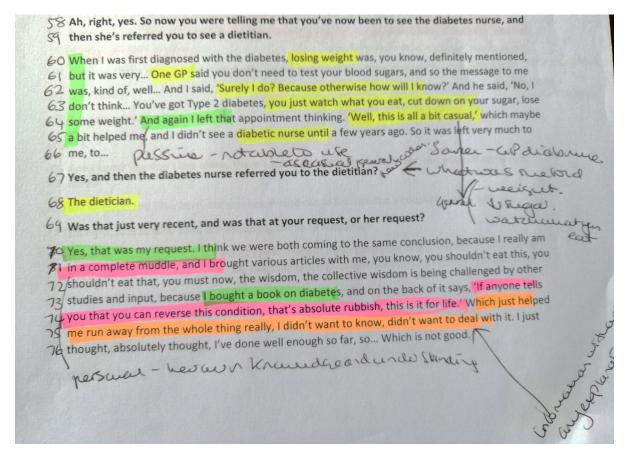
The analysis process consisted of the following stages (1-6), which are tabulated in figure 11; review; familiarisation with the data; overview; coding; developing categories; writing explanations (memos) to develop themes (Braun & Clarke, 2006). Excel spread sheets and NVIVO 11 (QSR International) were used to assist in the process of data management with Excel being used to categorise data during the initial stages of review and familiarisation and NVIVO being used once coding began.

Review, familiarisation and overview (stages 1-3)

Each data source was initially reviewed against field notes for each participant. Also the diaries were reviewed in order to refine the questions for each participant and after each interview the diaries were again reviewed and annotated alongside the field notes made during and after the interview. Similarly interview transcripts were annotated with their linkage to diary entries referred to by the participants.

Familiarisation was undertaken reading PDF copies of each diary and each transcribed interview. The recordings of the interviews were listened to alongside reading the transcripts for further familiarisation. Highlighter pens were used to identify broad topics and explanatory notes and ideas were recorded on the hard copies (figure 10). Quotes and text were categorised using Excel.

Figure 10 Hard copy familiarisation with data



Coding, developing categories, writing explanations (memos) (stages 4 and 5)

A line-by-line approach to reviewing the data was taken to identify individual codes. Individual participant diaries and interviews were analysed side by side. Also, diaries and interviews were analysed as individual data sources across the group of participants. This facilitated a thorough analysis of individual participant data and group data to be captured in the codes. Sections of text (from the transcribed interviews and diaries) and sections of the PDFs of the diaries were coded into NVIVO 11. A description was written for each code in order to enable allocation of relevant quotes or diary sections to the code. The data classified in each code was reviewed and explanations were recorded using the memo facility in NVIVO 11. Each memo was then reviewed. This enabled the identification and subsequent merging of overlapping codes and the location of disconfirming instances.

Theme development and research team checking (stages 6 and 7)

Similar codes were grouped into categories. For example, references to individual sources of information and experiences that impacted on the usability of information were grouped together in the category Usability. In this way relationships between categories could be seen and from this a

broad framework of themes was developed. These were discussed with the supervisory team, participants and lay groups. This discussion enabled a critique of the themes and following further modification and justification these were agreed. The broad findings were presented to the diabetes charity local support group and to the study participants (see appendix 6) to explore if the experiences were similar to theirs. Field notes state that the group members were interested that there had been little change in the presentation of nutrition information in the media in the intervening time between data collection and the presentation of the themes.

Figure 11 The stages of analysis where analysis (shown by the arrows) moved between data sources and between stages of the analysis

Tool	Raw data and Excel		In NVIVO (sources together)			Presentation	
Analysis stage	Stage 1	Stage 2	Stage 3	Stage 4	Stage 5	Stage 6	Stage 7
Method of analysis	Review	Familiarisation	Overview analysis, hand written notes	Coding (NVIVO)	Developing categories (NVIVO)	Developing themes	Respondents and research team checking
Data source					Cross sta	ge analysis	
Diaries	Diary review alongside topic guide and field notes	Annotating diary	Broad topics and main sources recorded				
Field notes		Cross Source and Stake		Grouping sections of data under headings. Writing memos	Review of memos. Combining codes	Relationships between categories	Themes were shared with respondents, lay groups and research supervisors
Interviews	Reviewing field notes made during and after interviews	Listening to recordings. Reading transcripts	Linkages with diaries				

3.8 Ethical issues

Ethics approval was obtained from the University of Hertfordshire Health and Human Sciences Ethics Committee, protocol number aLMS/PG/UH/00099(1). Written informed consent was obtained from potential participants after having explained the study and was confirmed verbally at the start of the interview (see appendix 6 for the documents used in this process).

Several potential ethical issues were identified during the study period which are worthy of further discussion. Participants were made aware that the diaries and the interviews were to be used only for this study and that their content would only be reviewed by the researcher and supervisors. Participants occasionally included in their diary information that could lead to identification such as the name of another member of the support group from which they were recruited, a family member or town or country (such as where they lived or visited). As cumulative information could lead to identification (Braun & Clarke, 2013, p. 169), in order to protect anonymity, information of this type was redacted in the PDF format of the diaries or in the Word interview transcripts. Also, the use of diary facsimiles to present the data may through the recognition of handwriting lead to the inadvertent identification of the diary authors. However, after having sought guidance from the Ethics Committee it was advised that sufficient steps had been taken through the redaction of potential identifiable information to allow the use of facsimiles in the publication of the findings from the study.

Research suggests that some participants take part in research projects in order to access care (Lawton, Fox, Fox, & Kinmonth, 2003; Townsend & Cox, 2013). In this study several participants commented (in diaries and interviews) on the lack of access to nutritional advice. Although the researcher is a dietitian, providing participants with nutritional information was not part of the study protocol. Participants were directed to their GP for advice regarding their diet, when appropriate. For example, Jennifer queried with the researcher if she should ask to see a dietitian. In this case the researcher agreed that she should enquire about this. As a dietitian the researcher followed their regulatory body, the HCPC's code of conduct regarding performance and ethics⁶ which states 'You must take all reasonable steps to reduce the risk of harm to service users, carers and colleagues as far as possible'

⁶ HCPC (2013) Standards of conduct, performance and ethics https://www.hcpc-uk.org/standards/standards-of-conduct-performance-and-ethics/

The researcher needs to balance these ethical and professional issues against ensuring that the method selected reveals rich and nuanced data for analysis and interpretation. Researchers should always question the processes of anonymising data and consider how far it is possible to completely protect participant identity and confidentiality. They should ensure that participants are clear as to the remit of the study. However, they should also be aware that there are likely to be situations where ethics approval and professional boundaries are challenged. Undertaking research projects that have the approval of ethics committees does not absolve the researcher of the need to act within their professional standards of conduct performance and ethics and the need to protect participant confidentiality, to be mindful of participant burden and to ensure informed consent.

3.9 Overview

This chapter has laid out and justified the details of the development and final methods used to collect and analyse the data in the empirical research study. The systematic review suggested further research was needed in the area of nutrition information practices which incorporated the complexity, hidden and tacit nature of practices. The research literature was used to refine the method relevant to the overall study objectives. The method (diary-interview) was piloted and the process discussed with lay groups. The process for data analysis with the analytic stages has been explained in order to emphasise the cross-source and cross-stage nature of the analytic process. The identification of themes and the way these were shared and developed with the research supervisors and lay groups and the ethical issues arising from the study and how they were managed has been discussed. The next three chapters present the findings from the analysis of the empirical research study. The first of these discusses the themes revealed by the participants that related to the context of information practice.

4 Chapter 4: The context of nutrition information practices

4.1 Introduction

The aim of this chapter is to set the scene for presentation of the findings relating to the information practices identified in chapters 5 and 6. This chapter begins with a description of the participants. This is followed by an explanation of the context for nutrition information practice, that is an exploration of what living with T2DM was like for the participants and how the presence of T2DM impacted on their day-to-day food experiences and activities. Experiences of being diagnosed with T2DM, coming to terms with their diabetes and participant personal characteristics and preferences, or dispositions, are explored. The section 'Living with T2DM' reveals the impact that T2DM had on the participants' daily lives. The chapter finishes with the food practices of the participants and how these are influenced by the presence of T2DM.

4.2 Description of the participants

This section outlines relevant details of the participants. Twenty participants were recruited from two counties in the east of England (county 1 n=11, county 2 n=9). Thirteen were female and seven were male, nineteen had T2DM, one participant (Danielle) did not have T2DM. She was married to another participant Christopher, who did have the condition. Participant details are summarised in the table below. Data consisted of nineteen diaries and nineteen interview transcripts. Data collection took place between June 2015 and April 2016.

While all participants completed a diary and took part in an interview, one couple (Matthew and Naomi) completed a joint diary and chose to be interviewed together. Text in italics is used to illustrate data interpretations and is accompanied by the pseudonym of the participant. In-text quotes are usually those from interviews, however, on occasion in-text quotes are from diaries. In these instances, the source i.e. diary is indicated.

Table 1 Study participants

Pseudonym	Age range in years at interview	Time since diagnosis in years	On medication for diabetes	Personal relationships
Andrew	70-74	23	Yes	
Christopher	65-69	7	Yes	Married to Danielle
Danielle	65-69	N/A*	N/A	Married to Christopher
Edward	75-79	5	No	
Frances	55-59	0.5	Yes	
Gary	60-64	7	Yes	
Helen	70-74	2	No	
Isobel	55-59	21	No	
Jennifer	65-69	0.5	No	
Lisa	50-54	1	No	
Matthew	65-69	5	Yes	**Married to Naomi
Naomi	70-75	11	Yes	**Married to Matthew
Oscar	55-59	1.5	No	
Penelope	70-74	15	Yes	
Ruth	55-59	1	No	
Susan	60-64	12	Yes	
Theresa	50-54	1	Yes	
Victoria	50-54	7	No	
William	80-84	20	Yes	
Yvonne	76-79	10	No	
Average	65	8	10 Yes	

^{*}Danielle did not have diabetes

^{**} Mathew and Naomi completed a joint diary and chose to be interviewed together

4.3 Diagnosis experiences

Participants contextualised their information practices through their diagnosis experiences. The way they experienced their diagnosis and their reaction to it was an indicator as to the way they set about managing their diabetes. Some participants described in detail the events that led to their diagnosis and the consequent T2DM management they experienced. For Andrew and Isobel, for example, the T2DM diagnosis was a memorable experience. Even though over 20 years had passed they were able to recall in detail dates of diagnoses, and treatments. For example, Andrew wrote in his diary the date that he became 'diabetic... but D-2 was not confirmed until [date seven years later] at [local hospital] where admitted to have [treatment]'. Some spoke of going to the GP with 'classic symptoms' (Matthew) such as tiredness (Jennifer, Penelope), feeling unwell (Susan), a medical problem (Gary, Ruth), which led to having blood tests for T2DM. While others spoke of having by chance a blood test for T2DM at a local testing station (Helen, Victoria) or a blood test as part of a health check-up (Lisa, Edward).

The events leading to the individual diagnoses were varied and personal to each participant. The signs and symptoms of T2DM are not obvious and diagnosis often comes about as part of other tests and investigations. The invisibility of the disease can mean that the diagnosis is unexpected or a surprise (even when the participant has a family history of T2DM). This lack of preparedness for the diagnosis impacted on how participants responded to 'having' T2DM. They explained how they reacted to the diagnosis with shock, fear and surprise even though through family connections they had experience of what T2DM meant and the common symptoms (Ruth, Theresa, Matthew).

Participants referred to the intangible, invisible nature of the disease, making comments such as: with T2DM 'you don't break out in a rash with a capital D' (Andrew), 'why was I not diabetic yesterday but I am today' (Gary) and being 'told to carry on as usual' (Helen). This meant that it felt as if the diagnosis was not serious, was unreal, fabricated and 'spurious' (Edward), making it difficult to come to terms with. The variations in diagnosis did not appear to be the main reason that impacted on how participants reacted. Instead, it seemed that it was the very nature of T2DM, being invisible with no outward tangible physical signs of a disease that made T2DM difficult to come to terms with, to take seriously and to accept.

Possessing the disposition of taking ownership was considered an asset by participants and typically led to the practice of using information to find out more about T2DM in order to be able to cope with having it. Participants felt that this asset was absent from those who were less interested in

finding out about T2DM, who did not consider their day-to-day actions and the impact that these actions would have on their condition.

In order to be able to come to terms with T2DM, accept it and 'cope with it' (Jennifer), when faced with a condition needing self-management, participants cited their own personal character and tendency to behave or react in a particular way, that is, a disposition: of being 'curious' (Edward), taking 'absolute ownership' (Susan), being proactive (Christopher). Indeed, Ruth said 'I need as much ...information as possible, my mind then settles and I can deal with what I need to deal with'.

Participants explained that this disposition of wanting to find out about T2DM in order to be able to self-manage was at variance to others they knew whose attitude was to "' live for today"' (Victoria).

Participants felt that people acted without any concern of how their actions may impact on the management of their T2DM and their future health. They felt that they would say "Oh well if I've got it I've got it, that's the end of that, I'm not going to bother finding out"' (Ruth). The disposition of taking ownership of the T2DM and being curious about the condition enhanced participants' ability to come to terms with it. This was considered an asset by participants, enabling them, they said, to come to terms with their T2DM.

4.4 'Rules of thumb' for living with T2DM

Participants were asked to record and to talk about their food related information experiences, which they contextualised with their experiences of living with T2DM. Although it may seem that for those who possess curious and proactive dispositions the process of coming to terms with and living with T2DM was simple and straightforward, participants' experiences suggest that living with T2DM remained a daily challenge. Once the diagnosis had been made the process began of learning to live with T2DM, a process of heuristics, of self-learning, leading to defining the principles of the way they decided to live with their T2DM. That is defining their personal and dietary 'rules of thumb'. Personal 'rules of thumb' were the outcomes that participants wanted to achieve through their self-management. These include weight control, control of blood glucose levels and an achievement of a specific HbA1c level. Dietary 'rules of thumb' relate to the food choices that participants intended to make that they believed would be 'healthy' for them in order to ensure that their T2DM was under control, however they were not overtly explained in their diaries or in their interviews. Although the 'rule of thumb' by which participants managed their T2DM remained hidden, tacit and unwritten they were nevertheless powerful influencers on the way participants experienced their T2DM.

The data revealed participants' experiences in ensuring they followed their 'rule of thumb'. The participants lived in a world of restraint and control, T2DM was described as 'being all around you' (Ruth) and 'controlling my life' (Penelope). Participants spoke of the importance of being 'disciplined' (Penelope) and controlling what they ate. If they were able to control what they ate, then their weight would be under control and the T2DM would be controlled. However, they often reported deviations from their 'rule of thumb' describing these deviations as 'cheating' with a resultant feeling of guilt. For example, Yvonne responded to her deviations from her 'rule of thumb' saying that she was 'eating all the wrong things'; William used the word 'cheat' to describe his actions and Lisa, William, Gary, and Yvonne said they felt 'quilty'. Controlling what they ate and removing specific food items from their daily intake meant that their dietary 'rule of thumb' was labelled as a 'diet' (Lisa), which consequently led to 'cravings' (Lisa, Frances, Susan) for the foods that they had been avoiding and a feeling of despondency when they gave into these cravings. One approach to preventing and managing these feelings of control, guilt and despondency was described as allowing the inclusion of foods that were not part of their dietary 'rule of thumb' as part of their daily eating pattern. For example, Jennifer said that she liked to 'have a little bit of what she fancies', Matthew commented that 'if you've not got a life what's the point of living [if you can't eat some of those foods?]' and Penelope wrote in her diary 'occasional treats [have] to be balanced by food intake for the rest of the day'. Participants felt controlled by the T2DM almost constantly and, as it was impossible to follow their dietary 'rule of thumb' all the time, they felt guilty when they perceived that they had not been able to. In order to manage the constant feeling of control and to prevent the feeling of guilt participants gave themselves permission to take a break from following their dietary 'rule of thumb'. This was a required break, a self- approved break from the day-to-day challenges of restrictions and restraint.

The word control was also used in relation to control over the body and control of the T2DM itself. T2DM control is assessed through the measurement of glucose in the blood using periodic HbA1c ⁷. This gives a measurement which can show how well blood glucose levels have been managed over a period of time. If blood glucose levels have been high for some or most of the time between the tests this will result in a higher HbA1c level. Some people with T2DM also monitor their own blood glucose levels on a day-to-day basis (self-monitoring) but this is only advised for those who are on insulin or who are on medications which can result in blood glucose levels going below safe limits

⁷ HbA1c is glycated haemoglobin. Diabetes UK defines it as representing 'your average blood glucose (sugar) levels for the last two to three months' https://www.diabetes.org.uk/guide-to-diabetes/managing-your-diabetes/hba1c

(hypoglycaemia)⁸. Not all the participants in this current study were advised to do this by health professionals. Those who were not advised to test their own blood glucose levels were concerned about not being offered the opportunity which led them to query the value of the periodic HbA1c levels commenting 'why such a long delay' (Frances-diary) to find out how well their T2DM was being managed. When told self-monitoring of blood glucose levels was not needed this led them to reflect 'well, this is all a bit casual' (Susan) and that therefore the T2DM was not so serious after all. Selfmonitoring in this way was considered fundamental in making the disease visible to them, 'otherwise how will I know?' (Susan) and it would give them 'something to hang onto' (Gary), helping them to understand how well their T2DM was managed. Some participants who had not been advised to undertake self-monitoring purchased their own blood glucose monitoring equipment. For example, Frances was used to checking her blood glucose levels after eating different foods. She undertook this in order to help identify potential foods to eat that would result in lower blood glucose levels and to give visibility to T2DM management between HbA1c tests. The process of self-monitoring blood glucose tests helped to return control over the T2DM to participants as it gave them a visible indicator as to their T2DM management. This fostered a greater understanding of their T2DM, helping them to come to terms with their T2DM, promoting self-management.

Participants' T2DM management and how they felt about their T2DM revolved around their blood glucose levels (either HbA1c or self-monitoring). Everything was 'great' (Ruth) if the blood glucose was at an acceptable level, i.e. the T2DM was under control. If it was not under control, then the participants felt that they were doing something wrong and 'due for a kick up the bum' (Christopher), needing to make changes in order to achieve control of the T2DM. Controlling dietary-related behaviours was felt to automatically lead to the T2DM being under control. If the T2DM was not under control this was because they had made mistakes in the way they were managing what they ate, and they had not exerted enough self-control. They felt pride when they were able to improve the management of their T2DM but also described feelings of 'frustration' saying, 'it can be quite demoralising that you put in all this work, you change so much of your diet and you don't get the results you hope to get' (Frances). Participants would record in their diaries the pride they felt in receiving positive feedback from their doctors with their blood results (Ruth). This contrasted with those who were finding it challenging and a 'struggle' (Frances-diary) to achieve the 'B.G. numbers'

[.]

⁸ NICE (2015) state that 'Self-monitoring isn't suitable for everyone with type 2 diabetes, and you should only self-monitor if your doctor or nurse advises it' https://www.nice.org.uk/guidance/ng28/ifp/chapter/Blood-glucose-and-target-levels

(blood glucose levels) they wanted (Frances-diary). These different experiences and reactions are illustrated in the diary excerpts below.

Figure 12 Ruth's and Frances's diaries: Reactions to blood tests results

Went to Doctors for Diabetic bloods Unice update, She's pleased as lower 44-from 47 or Unice normal.

Went to Doctors for Diabetic blood and Urine
Update, she's pleased as lower 44 from 47
and urine normal.

With so much going on in my life I sometimes struggle with staying committed to getting the diabetes undercontrol.

There are days when I feel more positive and days where I sniply cannot see what more I can do but the B.G. numbers continue to remain high.

With so much going on in my life I sometimes struggle with staying committed to getting the diabetes under control.

There are days when I feel more positive and days where I simply cannot see what more I can do but the BG numbers continue to remain high.

Ruth (uses HbA1c to monitor)
Top: Diary entry facsimile

Bottom: Diary entry transcription

Frances (uses HbA1c and self-monitoring)

Top: Diary entry facsimile

Bottom: Diary entry transcription

While the visibility of self-monitoring gave some feeling of control back to participants, when participants were 'put on' (Gary) medication, the control of the body was taken over by the doctor. The instigation of medication was out of their control reducing their ownership of their T2DM. Conversely before medication was imposed the ownership and control of the body stayed with the person with T2DM as in the case of Christopher who was not placed on medication straight away after diagnosis, saying 'I was asked to manage it myself' (Christopher). Participants spoke of asking for permission from their doctors to try to reduce medication and to not have the medication increased. For some, this feeling of empowerment to resist medication came from their own reading and research and knowledge of their own body and led to a decision to say to their doctor at their next appointment that they were 'not prepared to go back on it' (Edward). Indeed, this led one participant to feel empowered sufficiently to experiment with different amounts and timings of medications themselves without the direction of the doctor, explaining 'if I can reduce that into half a tablet rather than one ...so that the tablet would keep me ...under control' (Penelope). Participants who were on medications felt that this aspect of their T2DM was under the control of their doctor.

Only through being empowered by reading, research and knowledge of their own bodies were they able to take back control and ownership of and resist or manage medications.

While trying to come to terms with their T2DM and manage it, participants were also juggling the challenges they met in their daily lives including managing additional health issues alongside T2DM and family concerns. For example, Victoria recorded in her diary how the menopause impacted on her sleep patterns and her levels of anxiety, and Theresa wrote about how the pain in her leg prevented her from being able to take the exercise she needed. Family health also had an impact on participants being able to manage their T2DM. Jennifer explained in her diary that she was finding it difficult to learn more about T2DM while she had concerns about her 'poorly brother'; Lisa had a death in the family which meant that she was 'not really thinking about what [she was] eating'; and Frances, who was trying to understand how to manage her T2DM, was finding the time additionally 'stressful' (Frances-diary) as her mother was unwell. In this way T2DM could not be put on hold while participants focused on their immediate concerns, T2DM was still there, needing their attention. Even taking the decision to not think about what is being eaten, T2DM was still described as constantly present in the minds of the participants.

These experiences of being controlled, constantly needing to balance diet and medications and family life with the outcomes of pride and frustration, guilt and fear, highlight the opposing day-today experiences of living with a long-term condition such as T2DM. Participants needed to find a way of coping with their T2DM and what to do in order to follow their 'rule of thumb' alongside their experiences of coming to terms with T2DM. Participants coped with the feeling of being controlled by their T2DM by allowing themselves an approved break from following their 'rules of thumb'. However, when participants' daily lives prevented them from being able to follow their 'rules of thumb', that is without the approved break, the feeling of guilt returned. Although visible evidence of their diabetes management added to this feeling of control, this was in preference to their T2DM management being invisible, not knowing how well their T2DM was managed. For some this need to know how well their T2DM was being managed was such a strong disposition that they instigated their own self-monitoring as this is not automatically available to people with T2DM. Loss of control and a feeling of giving up control to their doctors was also felt when medication treatment was started. A feeling of control was regained when participants used knowledge resulting from information practice to inform the decision-making process regarding medication intervention. Participants' awareness of the importance of taking control of their T2DM and making their own decisions about how they managed their T2DM and when they kept to their 'rule of thumb' and

when they allowed themselves to divert from their 'rule of thumb' were coping measures to the ever present, yet invisible, T2DM and the day-to-day feelings of guilt.

4.5 Food practices for managing T2DM

This section explains the impact that T2DM had on food practices. Shopping and cooking practices were shared with families, partners and friends. Shopping was often a joint event undertaken 'together' (Matthew). The division of cooking responsibilities between different members of the household was a common occurrence as it seemed 'fair' (Ruth) when partners also happened to possess cooking skills. However, in order to ensure that the food prepared met their 'rule of thumb' for them and their families, participants would ensure that appropriate food was the 'only option' (Ruth) to use, take a 'lead' (Isobel) in what was prepared and made available to eat and guide those preparing food on which food items to 'not' use and which foods to 'now' use (Victoria). While cooking was a common activity for the immediate family and partners, it also featured as an activity for the extended family. Several participants had a role in childcare for grandchildren either on a regular basis or periodically. While the time with grandchildren was valued, eating with them had the potential to impact on the ability of participants to follow their dietary 'rule of thumb' because '[our grandchildren] want to eat different things' (Christopher). However, it was also seen as an opportunity to ensure that the younger generation ate food which the participants believed was healthy 'because they are going out into a world which is...obesogenic' (Isobel). Family and friends were a source of support about the decisions made about what to eat. Discussions were held between friends and family about which foods were considered healthy and support was provided at mealtimes assisting participants to meet their dietary 'rule of thumb'. These practices helped participants to 'regain and retain focus' (Edward-diary) on what was healthy for them to eat. In this way having T2DM was integrated into the decisions made when undertaking daily food practices of shopping, cooking and eating and these necessarily revolved around family and friends. Daily life impacted on the ability of participants to meet their dietary 'rules of thumb' which they managed by ensuring they had the support of family and friends by engaging and involving them in their T2DM management through food practices.

The source of the everyday skills, knowledge and beliefs used by participants in managing their T2DM appeared to be hidden and taken for granted. Participants spoke about food that they considered as 'healthy' for them to eat, i.e. their 'rule of thumb', and some participants suggested that beliefs about these foods came from childhood. The value of these childhood experiences varied. For some they were seen as 'lucky' (Lisa) to have had an early grounding in what was

considered ideal for people with T2DM to eat, for others their experiences were limiting in their 'traditional' approach (Gary, Oscar). Participants were concerned about people who had not had childhood food practice experiences which introduced them to the basics of where food came from and who grew up 'not knowing that carrots grow underground' (Frances). This limited food practice experience would impact negatively on their knowledge and beliefs about which foods were 'healthy' to eat. The link with childhood experiences and skills, knowledge and beliefs about food that is 'healthy' to eat suggests that food practices are learned and become embodied practices. Indeed, the process of learning, that is, how participants knew and believed what food was 'healthy' for T2DM was hidden.

Everyday food practices were further contextualised through diary entries and interview conversations by all participants in a way that suggested that decisions about what to eat were taken for granted and automatic. Almost all participants included in their diaries what they regularly ate. Usually this would be individual meals however for some the entries included what they ate over a full day and a few participants recorded what they ate over part or most of the diary period. These entries appeared to be used to highlight how they were following their dietary 'rule of thumb'. Only occasionally did participants record times when they felt they had not followed their dietary 'rule of thumb'. In this way the diaries appeared to be a tacit way of identifying participants' dietary 'rule of thumb' and highlighting specific decisions made. For example, William included what he ate everyday over the diary period and emphasised cooking processes which he identified as meeting his dietary 'rule of thumb'. The regularity of his meal pattern and the completeness of his record highlight the embodied nature of the way he self-manages his T2DM. Victoria also recorded what she ate (see diary extracts below). Her records indicate the way that her food practices were woven into her everyday life of exercise, work and childcare. Alongside the entries about what she ate and her daily activities were explanations as to what had influenced her to make those food choices. She recorded that she ate porridge with cinnamon for breakfast. Next to this entry Victoria explained that this was because she had read that porridge helps to lower cholesterol and cinnamon helps to manage T2DM; as a consequence, she is no longer taking statins, which are used to control serum cholesterol.

Figure 13 Victoria's diary: Link between food choice and knowledge



Got up Did yoga for 15 mins had a bit of bad night Menopause. Breakfast Porridge and cinnamon with Skimmed milk about 6 am. I had previously read that porridge is Great for lowering cholesterol and cinnamon is good for diabetes so have been having this for breakfast every morning for a few years Now off statins.

Victoria: Diary entry illustrating food eaten and

activities.

Top: Diary entry facsimile

Bottom: Diary entry transcription

Victoria: Diary entry illustrating decisions made about

food eaten.

Top: Diary entry facsimile

Bottom: Diary entry transcription

Diaries were also used to record when they were not necessarily able to keep to their 'rules of thumb' and words which had a judgemental tone were used. For example, Frances (see below) used the term 'good' to record in her diary that she had kept to her dietary 'rule of thumb' and then 'down hill' to describe her behaviour when she 'gave in' and had a chocolate, which she felt that she should not have had.

Figure 14 Frances's diary: Cravings

I feel I was good food wise all day
but the evering went down hill.

I had a craving for chocolete and I gave
in and ate some.

I feel I was good food wise all day But the evening went down hill. I had a craving for chocolate and I gave in and ate some

Frances diary entry facsimile

Frances diary entry transcription

Whilst food decisions were embodied and eating was woven into everyday activities, participants used their diary entries to tacitly identify their dietary 'rule of thumb', to justify their decisions and to identify when they had not necessarily kept to their dietary 'rules of thumb'. Their food decisions were based on embodied knowledge and beliefs about what was 'healthy' for them to eat in order to self-manage their T2DM. The regular inclusion of what was eaten in the diary entries was an

indicator that food decisions relating to T2DM were integrated into their daily lives and underlined the tacit nature of their T2DM, their dietary 'rule of thumb' and their food practices.

Shopping

Food shopping activities were recorded in diaries and explored in the interviews. For some food shopping including decisions about shopping venues was a key part of ensuring that they ate food that met their dietary 'rule of thumb' for themselves and their families. However, for others the process of shopping was automatic, taken for granted. Penelope explained 'I don't skimp on food. If food is good like, I'll buy it. And that's the most important thing, health is the most important' and went on to say 'it's best to get it from the ground, when it's fresh. And that's why I go to the market, it's fresh from the ground. It hasn't been anywhere else'. For Penelope the source of the food was crucial to ensuring that the food she purchased met her dietary 'rule of thumb' for herself and her family. Jennifer shopped in a variety of venues however she was less inclined than Penelope to make specific shopping trips, instead saying 'wherever I am I will shop'. However, Theresa did not like the physical process of shopping at all and would use online shopping to ensure that she was able to purchase what her family needed. Although, for some, shopping was a considered activity with venues selected in order to ensure that food that met their 'rules of thumb' was purchased, for most this process was a tacit mundane, taken for granted activity.

Apart from the shopping venue and food quality, knowledge and beliefs about the nutritional value of the food were identified as an influence on which foods were purchased. Participants relied on their knowledge and beliefs about the nutritional value of foods that were home cooked, recording in their diaries 'Sorry all home cooked & no info' (Isobel-diary). Penelope however carried extensive knowledge about the nutritional value of the food she ate and frequently included this information in her diary. Penelope's diary entries began with an explanation of what she had purchased. They were then followed by an explanation as to why she believed that food was 'healthy' for her and her family. She wrote in her diary for example that spinach was a good source of lutein 'which may help to protect against cataracts' (from which she had suffered); that the seeds in the multi-seeded brown bread she had bought 'have a low glycaemic nutritional food value. Packed with protein, good fat and fibre, good for levelling blood sugar'; and that having purchased a half salmon from the fishmonger she wrote in her diary 'Salmon is rich in omega-3 fatty acids. It helps prevent heart diseases. It is a protein food and help[s] maintain brain power as you age'. Similarly, Victoria and Isobel recorded the nutritional properties of the foods they ate. However, most participants when referring to the influence of the nutritional value of foods on their food purchases spoke about the

nutritional information which they had seen on food labels, and the way it had influenced (or not) their food purchases.

While there were many limitations to the accessibility and usefulness of the information most spoke about using the visibility of the traffic light guide as this system 'stares you in the face' (Yvonne). Some however also looked at the back of pack information where the ingredients and nutritional values of the product could be found. For those that used the back of pack information, this was more useful than the front of pack information as this was where the amount of carbohydrate in a food could be found. The amount of carbohydrate in a food was considered more useful in being able to contribute to the understanding of how the food could impact on their T2DM management. Most however wrote in their diaries and spoke in the interviews about how food labelling information did not contribute to their decisions about food to buy for their families. Instead shopping decisions to ensure food provided for themselves and their families met their dietary 'rule of thumb' and was what they believed would be 'healthy' for their families appeared to be tacit and to rely upon the application of embodied knowledge and beliefs.

Cooking

Participants recorded and spoke about how they cooked for their families or how they were cooked for, such that cooking with T2DM was integrated into the daily cooking practices. For example, Jennifer said she 'more or less cook[s] the same way'; Lisa explained that the food prepared was in such a way that it led to 'benefiting the whole family regardless of whether they have T2DM or not'; and Yvonne said that she reduces the amount of sugar when she bakes a cake, commenting that 'nobody has moaned' that the cake is 'not sweet enough'. The contextualisation of what was considered 'healthy' food to eat suggested that the practices were assumed, taken for granted and adopted over time. This was without an overt influence of what was believed to be 'healthy' to cook for T2DM. Cooking for T2DM was woven into everyday family life and had become a tacit food practice.

While participants spoke about general cooking practices for T2DM, they also referred to specific food practices in order to manage T2DM. Some examples were: control of portion sizes, a reduction in the use of salt and consumption of salty foods, and an increase in vegetable intake. Controlling portion sizes was a way of minimising the impact of the T2DM by continuing to make decisions about what to eat as they had before they had T2DM, but to limit the portion size consumed. For example, Lisa explained that when a friend gave her a cake, the family ate the 'majority' but when she did

have some she had 'small portions'. The practice of reducing salt intake was undertaken through 'buying foods that have low salt' (Jennifer) or by trying 'to cook with less salt' (Lisa). The emphasis on increasing consumption of vegetables was illustrated by participants through for example: how they went about using more vegetables generally; by including different types of vegetables; or by simply ensuring more vegetables were available for use in the household. For example, Oscar commented 'these days we put more vegetables in'; Penelope explained in her diary that she served an 'additional veg for dinner'; and Theresa made sure that there was a supply of vegetables throughout the year by supplementing the vegetable crops from her allotment with a 'family veg box' that was ordered from the internet and delivered to her home.

Although cooking for T2DM and specific food practices to manage T2DM were emphasised, the nature of the cooking process itself was also considered an important food practice for managing T2DM. Indeed, the cooking process was considered so important to managing T2DM, its description was emphasised, referred to as 'cook[ing] from scratch' (Victoria, Theresa, Gary, Lisa) so that it was clear that food was being prepared without processed food items. This process was a way to ensure that what was eaten was 'healthy' for the participants and their families. 'Cooking from scratch' enabled the adaptation of foods to ensure they met their dietary 'rule of thumb', so that they knew 'what went into food' (Gary), and facilitated the avoidance of processed foods. When participants had cooked from scratch they were rewarded with a 'good' feeling (Gary). To ensure the reward of the 'good' feeling, the cooking process did not need to be undertaken by participants themselves, instead cooking that was shared or delegated to those with skills was also considered 'healthy'. For example Oscar, Gary, Ruth and Lisa shared cooking with their partners, Susan delegated cooking to her husband as she explained that 'he's always been a much better cook' while Christopher explained that 'it's not a skill I have ever learned...Danielle [my wife] has continued to do it for me'. However, cooking skills were a priority to develop for those without these skills. For example, Edward explained that having obtained cooking advice from his family, he will be 'switching to homeprepared meals for lunch...because you know what [the food is] made from' (Edward). Cooking was a taken for granted embodied food practice that was undertaken to ensure that what was eaten met the dietary 'rule of thumb' enabling avoidance of 'unhealthy foods'. The process helped to ensure that participants were able to follow their dietary goals and came with a reward of a feeling of pride having taken the time to prepare healthy food.

Whilst cooking skills were indispensable in enabling the process of cooking from scratch implicitly leading to an avoidance of processed foods, the use of recipes and specific cooking methods were

needed in order to ensure the foods prepared were 'healthy'. Participants described how recipes would be tried and tested and as Danielle explained 'you either decide whether it's good or not then it either falls into my regular stuff or it doesn't get done again'. Recipes that had been incorporated into food practices were written out in diaries and recalled verbatim during interviews with favourite recipe books being identified. However, what was more common was the reference to standard methods that were part of everyday food practices and were used by participants to assist them with their dietary goals. For some the reference to cooking methods as opposed to recipes appeared to be related to the lack of specific recipes for people with T2DM or rather recipes that appeared to meet the T2DM dietary principles. For example, Susan spoke about the disappointment that a recipe on a T2DM charitable organisation website used sugar which she felt was not appropriate for people with T2DM and said in her interview 'but I thought "Well, no, hang on a minute, this is still talking about using sugar". For some, recipes formed a core part of their food practices to ensure food that was consumed was 'healthy' for people with T2DM, however recipes specifically for people with T2DM did not appear to exist and so a common approach was to rely on specific cooking methods instead to ensure that food prepared was 'healthy'.

Many participants referred in their interviews and diaries to specific cooking methods that they used to help them meet their dietary 'rule of thumb'. For example, William recalled his wife using a fat spray on oven baked chips, this avoided deep frying the chips and resulted in a lower fat intake; Andrew recalled putting lemon juice on brussels sprouts to encourage him to eat more vegetables as this made them taste 'rather good'; Victoria recorded in her diary how when making a curry the onions would be 'softened in microwave in water', in order to use less fat in cooking and explained in her interview 'I do it all the time, with anything...'. Recipes and methods that had been used previously were then relied on to ensure that what was eaten was 'healthy' for them, without needing 'to stop and think about it' (Matthew). The process of cooking from scratch elevated the use of cooking skills to an essential approach to managing T2DM. Recipes and additional cooking practices were used to ensure that cooking from scratch met dietary goals. However, although some participants used recipes designed for people with T2DM, the majority relied on additional cooking practices to make sure that the food consumed was 'healthy'. In this way cooking from scratch was incorporated alongside specific cooking practices into their daily T2DM food practices.

In this section I sought to illustrate the way food practices were social, tacit and integrated into the daily lives of the participants. Decisions made about food that met their dietary 'rule of thumb' for T2DM were considered implicitly 'healthy' and suitable for everyone in the family. Shopping

ensuring 'healthy' foods were chosen, the specific decisions made were tacit and relied upon embodied knowledge. Although food labels were a visual cue, the nutritional information did not often influence the decisions made. Cooking practices and the very process of 'cooking from scratch' were also focussed on ensuring dietary goals were met. Recipes that had been identified as healthy were committed to memory and tacit healthy cooking practices were used. Although sources of recipes could be identified, the cooking practices appeared to come from embodied knowledge about what foods and processes were likely to be 'healthy'. Whilst specific dietary goals of participants were not recorded, there was commonality of cooking processes utilised in order to self-manage T2DM. These food practices were carried by the participants and were embodied across the group. The use of these processes would help to ensure that the dietary 'rule of thumb' was met and T2DM was managed. The practices were informed by hidden and embodied knowledge.

4.6 Summary

This chapter described the participants, the way they used their diaries, their T2DM experiences and food practices as a context for the next two chapters. The personal context of T2DM and food practices was explored. Diagnoses experiences affected the way that T2DM was accepted which impacted on the way that participants were self-managing their T2DM, however, the possession of personal characteristics specifically of curiosity and a proactive nature were also key in facilitating participants to self-manage. People with T2DM live in world of dietary, personal and bodily control with a constant feeling that diabetes was all around them and a feeling of guilt if they strayed from their personal 'rule of thumb'. Personal dispositions of empowerment and the individual embodiment of T2DM were needed in order to cope with this all-pervasive feeling of control.

T2DM and food practices were found to be integrated and the approach to integrating T2DM into their food practices was tacit, the source of these T2DM food practices being hidden. Common food practices such as cooking from scratch and the adaptation of recipes were considered essential in enabling self-management which had become embodied and relied on embodied knowledge and skills. The personal context of T2DM and T2DM food practices serve as an introduction to the embodied diabetes and nutrition information practices explored in the next chapters.

5 Chapter 5: Nutrition information practices

5.1 Introduction

This chapter explores the nutrition information practices relating to the sources of nutrition information referred to by all participants: food labels and peers. Information practice is broken down into the three core elements of the practice framework: material, meaning and competency. Materials relate to the resources accessed and used as part of the information practice. Meanings refer to the reasons for participants carrying out the information practice and are what drives it. Competencies relate to the knowledge and skills held by the person with T2DM (the carrier of the practice).

All participants discussed using food labels either in their diaries (13 out of 19 diaries included food label samples) and/or in their interview. All participants also referred to interaction with peers as a source of information practice. The term peer is used across this thesis to refer to anyone who has T2DM (or who cares for someone with T2DM). Other people that participants may be in contact with to discuss their T2DM such as HCPs and family and friends are excluded from this definition. The chapter begins with an explanation of the material aspect of each source as experienced by the participants, followed by the meanings, that is what drove the information practice and finally the competencies that the participants needed and or used in being able to make use of the source. Food labels are explored first, followed by peers.

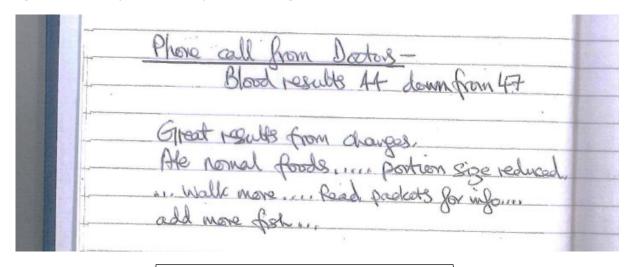
5.2 Food labels

The aspects of food labels talked about by participants included the front of pack information and the back of pack nutrition information and ingredients list sections. The aim of the front of pack system is to provide a comparison of the nutritional value (fat, saturated fat, sugars and salt) of a portion of a food item with what is considered a healthy amount for an adult whose energy requirement was 2000kcal per day. The colour coding system is referred to as the 'traffic light colours' (BNF, 2018; Department of Health, Food Standards Agency, & British Retail Consortium, 2016 p. 31) with red denoting a high (unhealthy amount), amber a medium (neither healthy nor unhealthy) amount and green a low (healthy) amount of the nutrient. At the time of the study this system is voluntary and so not all foods display the traffic light system, using instead the 'Guideline Daily Amounts' (FDF, 2020). The back of pack information is mandatory and includes the energy value and the amount per 100g of fat, saturated fat, carbohydrate, sugars, protein and salt

(Department of Health and Social Care, 2017 pp. 7,9). Nutritional claims such as 'low fat' may also be found on the front of the food packaging (See Department of Health and Social Care, 2017 p. 7). Participants referred to food labels (front of pack, back of pack nutrition information and ingredients) as one complete resource, but when the process for using food labels was explored in more depth during the interview it became apparent that different parts of the food label yielded different experiences for the participants. Food labels overall were considered by most participants as essential sources of nutrition information in assisting people to manage their T2DM. When nutrition information is absent from unpackaged food items such as bread purchased from bakeries, this made finding out 'what's in something is quite difficult' (Danielle).

While food labels were a readily available source of information the process of using them was an everyday practice in managing their T2DM. For example, Ruth emphasises in her diary the changes she had made to her self-management that she had felt had impacted on her blood results. This included looking at food labels.

Figure 15 Ruth's diary: Food labels as part of self-management



<u>Phone call from Doctors-</u> Blood results 44 down from 47

Great results from changes.

Ate normal foods.....portion size reduced.

...Walk more....read packets for info....

Add more fish...

Ruth diary entry

Top: Diary entry facsimile

Bottom: Diary entry transcription

The regular use of food labels for participants appeared to have been influenced by a health care professional such as in the GP surgery or during a structured education programme. Participants described experiences such as being told by a practice nurse to 'always look at the sugars [on food labels]' (Yvonne) and being guided on 'how to look at them '(Ruth) during structured education.

Traffic light symbolism

Example traffic light panels from food labels were often included in participants' diaries. However sometimes these were included without comment, suggesting the ready availability of food labels as a source of nutrition information. While the inclusion of food labels implies the tacit nature of using food labels in food choice, the action may also indicate active identification of food labels as a source of information. However, the lack of comment or explanation also suggests the serendipitous nature and or the assumed nature of traffic lights as a source of information. Participants had an embodied understanding of the symbolic nature of the colour coding used in the traffic light system. They felt that foods with red labels were foods that should be avoided. For example, Oscar explained that when shopping with his partner they applied their 'rule of thumb' to shopping decisions. He said 'we've sort of made an unwritten rule between us anything with two reds on we don't touch now'. Participants found that the traffic light system was also applied to online recipes. For example, Yvonne said '...it stares you in the face ...Its red...' and when discussing the recipes, she said, 'when its high I throw those recipes away'. The concept of red denotating danger was used in general discussions about food. For example, when talking about cereals with added sugar, Matthew said 'you know 'porridge with honey', well immediately that goes red light, red light!'. Participants had the embodied belief that as the red colour in the traffic light panel meant 'stop' (do not eat)⁹, this also implied that the food would be dangerous for them to eat. For some the term 'traffic lights' had entered everyday language being used as shorthand when wanting to define foods as potentially unhealthy as Gary explained in his diary when he was faced with an ice cream dessert at a friend's party which 'did not come with traffic lights'. For Gary the use of the words 'traffic lights' in relation to foods implied that the food was unlikely to be healthy. There were few references by participants to the identification of foods that were labelled green and the selection of these.

The traffic light system was deeply embedded in the minds of the participants such that even when the label colours were absent from front of pack or the labels were 'white', or a 'sepia colour' (Andrew), they were referred to as using the 'traffic light symbolism' (Andrew) (that is referring to

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⁹ As in traffic lights used in the UK (Schuldt, 2013; Vasiljevic, Pechey, & Marteau, 2015) where the red light means 'stop' do not drive.

the format of the traffic light panel). Andrew wondered why the current format was not vertical as in traffic lights as opposed to the usual horizontal especially when there is no colour. He said, 'what's the point of doing a horizontal ...traffic light logo and no colouring at all...?'. The concept of the traffic light system was so powerful that even when colours were absent, and the format did not relate to traffic lights, the participants understood that the front of pack labels aimed to communicate whether a food was healthy or not healthy.

Since the ideas behind the colour-coding system on the traffic light system are embodied, participants felt that 'for people who are not mathematic or understand percentages [the traffic light system] is really good' (Victoria). In this way Victoria felt that people would not need to look at the figures on the back of the food packet and interpret them. Instead as the nutritional value has been reviewed and encapsulated in the traffic light panel, people could make decisions on that basis.

However, participants also felt that the concept of the colour coding should be applied to the back of the pack. Oscar said that each nutrient could be coloured using the 'red green orange banner' and Gary wrote in his diary that the sausage roll he had eaten was labelled green for sugar, red for fat but when looking at the back of the pack that the fibre, protein and carbohydrates had no 'comments by them' and he wondered 'what does that mean for us diabetics?' The concept of the colour-coding system in the traffic light panel on the front of the pack was considered so universal that participants felt that it could be applied to other aspects of food information such as the back of the pack to help people with T2DM to make decisions.

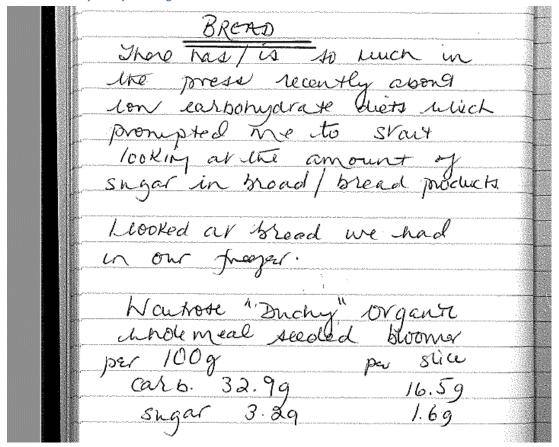
Some participants however did not consider the traffic light system useful. Matthew and Naomi did not use the traffic light system, because the system did not provide them with the information that they needed. The important information for them was how much carbohydrate was in a food which is found on the back of the pack. So, they 'ignore the traffic lights because the traffic lights don't tell you anything about carbohydrate, they tell you about sugars' (Matthew). The symbolism of the traffic light system was a concept that had been embodied and tacitly understood by many participants. However, while the system appeared to assist the majority in managing their T2DM by helping them to identify foods that were unhealthy, for some as the system did not highlight the nutrients that they needed to know about in order to manage their T2DM, this meant that the system was not valuable to them.

Back of pack labelling

Some participants used the 'detailed' (Lisa) mandatory back of pack nutritional information and the ingredients list to help them make decisions about what to eat. The nutritional information was checked for specific nutrients, the ingredients list was referred to when checking for example if a food contained a specific ingredient which a participant wanted to avoid (such as meat for vegetarians) and to interrogate a nutritional claim on the front of the pack to see if it was true. For these participants the back of pack nutrient list was key in helping them to decide which food and how much to eat and they compared the information against their 'rule of thumb'. For example, Matthew and Naomi balanced out the amount of carbohydrate in the food with other foods they were going to eat in the meal. Their aim, their 'rule of thumb' was for the total amount of carbohydrate in the items in the meal to be 'about thirty grams maximum in a meal' (Matthew).

Susan had a tacit appreciation and applied a 'rule of thumb' about foods that she felt would be unhealthy for her to eat. In her quest to find foods that had a low sugar content she needed to look at the back of pack information. She examined in detail the information which identified how much sugar was present in the foods she ate. In the section below from Susan's diary, she explains that she started to look at the carbohydrate and sugar in the bread that she usually ate.

Figure 16 Susan's diary: Analysis of sugar in bread



BREAD

There has/is so much in the press recently about low carbohydrate diets which prompted me to start looking at the amount of sugar in bread/bread products

I looked at bread we had in our freezer

Waitrose 'Duchy' Organic wholemeal seeded bloomer Per 100g per slice carb 32.9g 16.5g sugar 3.2g 1.6g

Susan diary entry

Top: Diary entry facsimile

Bottom: Diary entry transcription

Susan identified that she became interested in looking at the amount of sugar and carbohydrate in the bread. She started by looking at the bread that she normally eats at home and copied this information into her diary from the information on the back of the food packaging.

Ruth also looked at the back of the pack information but she was more interested in the ingredients as she wanted to compare two products in order to decide which to buy. Ruth wanted to avoid the sweeteners added to fruit squashes bearing the nutritional claim of 'no added sugar' and so in the supermarket compared the amount of sugar in a normal squash with the 'no added sugar' squash. She explains that 'they say sugar free, but then they've added something to it that actually takes it onto the carbohydrate side a bit higher'.

Andrew analysed the label on the kiwi fruit he had eaten and comparing this with his 'rule of thumb' for how much sugar he could have in a day, said 'I have two kiwis in one go then that is half the daily amount of sugar'. The record in his diary indicates that he noticed that kiwi fruit are low in fat and consequently high in sugar and count as '1 of 5 a day [portions of fruit and vegetables]'.

Figure 17 Andrew's diary: Analysis of the nutritional information on a bag of kiwi fruit

DayDate
Have you come across any information about what to eat today?
Record for each piece of information.
• the approximate time of day 7—9pm Seemed a good buy
the approximate time of day 1 - 9pm Seemed a good buy the type and source and summary of the information PHOTE. were you able to use the information? ###
 did you search for the information or just came across it?
on Purchase
(8.) (Fesco) Repin at Home KIWI
(1) Plastic carrier tog NOT T/ lights babelled at all, "E value on so low except SUBARS. 18%
"E values are so low except SUBARS. 18%
(ii) 2 Kini fruits > 10f5 a day
(
(iii) notice how Sugars 164 gms (2 faits) 18% Salt < 0.2 gms (-H) < 2% Fat 0.8 gms (-H) 2% (bertainly conforms to the saying if its low in FAT, its high in SUBARS and VICE VERSA).
Calt 40.02 pms (-H) < 2/0
1 00 m (-H) 2%
Jat 0.8 yms
(fertainly conforms to the saying if is low in
COLARS and VICE VERSA).
FAT, is high in stand
Consoc—
(iv) lend to eat them in 2s. (but 16.4 gms Swanes - such greed? - but only 10f5 a day)
(1) Sout mely 1045 a day)
such greed - mi only
111
(v) N/A.
2000年 18 中海 · 西西

Day	yDateDate				
Have you come across any information about what to eat today?					
Record for each piece of information:					
•	The approximate time of day 7-9 pm Seemed a good buy				
	at its FULL PRICE				
•	The type and source and summary of the information <i>PLASTIC</i>				
	PACKET				
•	Were you able to use the information? Yes				
•	Did you search for the information or just <u>came across</u> it?				
	on purchase				
(v) N/A					

Andrew diary facsimile

Andrew diary transcription in blue text

However, Andrew's analysis of the food label indicates his concern that, while two kiwi fruit provide half his sugar allowance, in his view they only count as one of the 5 portions of fruit and vegetables per day that he should be eating. So, by consuming the further 4 portions of fruit and vegetables he would be likely going over his sugar allowance.

The back of pack information was used to interrogate the nutritional value of the food. The information gave a specific figure which could be applied to the participants rule of thumb and a decision made about whether to eat the food. While this process provided an objective measure, participants also voiced their mistrust in food labelling. Christopher was concerned about the use of the reference intake saying 'it's just a tool used by the food industry to mask the deficiencies of the product' and Gary, Ruth and Susan were concerned about the nutritional claims especially related to 'low calorie' or no added sugar when discovering that there was sugar in a product and saying 'now wondering how much we can trust labelling' (Gary-diary). Participants held a lack of confidence in the food industry and when food labels were analysed, they identified that the ingredients did not appear to match up with the nutritional claims.

The meaning of sugar as an ingredient and nutrient.

Sugar was the most common aspect spoken about in relation to the management of T2DM and the nutrient and ingredient most commonly referred to on food labels. Participants beliefs about sugar appeared to influence their information practice with food labels. Their embodied beliefs about sugar in processed foods and unprocessed foods and about sucrose influenced their information practice with food labels.

As participants had 'become very aware of sugar' (Susan), it was seen as an ingredient to be avoided as it was considered 'dangerous' (Matthew), 'bad for everybody' (Danielle) and 'statistically if you're drinking lots of sugary drinks you're at higher risk [of developing diabetes]' (Matthew). They felt there was a need to be vigilant about sugar as so many foods have it added to them and children particularly are 'brainwashed' (William) into wanting and liking these foods. Participants appeared to be hyperconscious about sugar in foods, as it was viewed as a hazardous nutrient that has the potential to cause diabetes and is often added to foods marketed to children.

Their beliefs about sugar were not just about sugar that was added to foods it also related to sugar that was naturally occurring in foods as a nutrient. For example, Susan said that as her son 'has to be very fit for his work' he must take care of how much sugar he consumes. He explained to Susan when

she was eating a banana 'but that's just sugar, that banana is just sugar'. Sugar was a nutrient that was of concern to participants whether it was an ingredient or whether it was naturally occurring in a food.

These beliefs about the amount of sugar in food contrasted with the use of sugar itself that was added as a sweetener to drinks. Sugar in this form was considered natural. This was at variance with the views participants held about 'chemical sweeteners' (Susan) added to foods as an ingredient in processing. For example, Ruth referred to them as 'horrible' and to which Susan described herself as being 'anti'. The use of sugar as a sweetener was believed to be acceptable as sugar was considered a natural food and preferable to synthetic sweeteners.

Participants' beliefs about sugar and sweeteners had the potential to influence their information behaviour relating to food labels. They were interested in the total amount of sugar in a food item and its contribution to the overall sugar intake in the diet and did not appear to be able to distinguish between total sugars and free sugars. Although Lisa and Victoria selected yogurts that did not have any sugar added they also noted the importance of balancing out the sugar consumed in other foods across the day. When Lisa was looking at the food label on the yogurt she thought 'what else am I taking sugar in?'. Victoria explained that the sugar-free yogurt with fruit that she had been given by a friend still has 'a lot of sugar in it' and now she has 'natural low-fat Greek yogurt, which has got no fruit in it and virtually hardly any sugar'.

Susan was also conscious of the importance of the amount of sugar she consumed, however she used her diary to explore and record the foods she consumed which had sugar. These included milks, crackers, diet biscuits, bread and breakfast cereals. She notes in her diary that she was 'shocked' to see how much sugar was in milk and identified almond milk as the healthiest for her as it was low in 'Carbs' and because she was 'aware that almonds do not have any cholesterol'. In her review (in her diary) of the food labels on the packets of crackers she also identified a lower-sugar cracker which had '1.1 g of sugar per cracker [as being] a good choice to make'. However, her main interest was in the amount of sugar in breakfast cereals. This was particularly because her favourite breakfast cereal was supplied to her by friends from overseas and she noticed that the same product here in the UK had a higher amount of sugar in it. She then found that the company had changed the recipe of the cereal made in the UK and were trialling it at a local supermarket, so she rang the customer services to thank them:

'And I actually rang them up, I rang up the company and spoke to the customer, or consumer line, and I actually said, 'Thank you so much for reducing the amount of sugar in bran flakes,' and he said, 'It's been very controversial. A lot of people have rung up, and they're really upset with us.' And I said, 'For heaven's sakes, they can add their sugar to it, whereas if it's already in it you can't.'(Susan)

Sugar was the most frequently reviewed ingredient and nutrient included in food label information shared in diaries and discussed in interviews. While its presence in processed foods was viewed with aversion and considered an ingredient to be avoided, its use as a sweetener was considered preferable to using chemical sweeteners. Many participants were diligent about applying the information about total sugars on the back of the food packaging to their food choices. They were surprised and concerned when they saw how much sugar was in a food item and selected products with the lowest total sugars whether the amount of sugar in a food item was significant or not.

The competencies of knowledge and numeracy skills

Participants often felt that they lacked the competency, including knowledge, to be able to interpret food labels. For example, Andrew said they were 'far more, far more complicated than, than one would ever imagine', Jennifer said that she was regularly checking food labels and yet she wrote in her diary 'Forever looking at labels on food. Getting more confused over CARBS, protein etc. just can't seem to take anything in' and Ruth simply said, 'it could be simplified' and 'there has got to be an easier way' to present the information on the food label.

Participants believed they needed nutritional knowledge in order to be able to make use of the information on food labels. Lisa felt that to not have this knowledge would mean that the information would be overwhelming and 'people [would] switch off after a while'. Andrew said he was confused when trying to understand the difference between free sugars, and naturally occurring fruit sugars which together make up the figure for the total sugars recorded on food labels. Susan described her approach to food choice as 'guesswork', her lack of knowledge as 'pathetic' and her consequent feelings when she ate foods that she did not consider healthy as 'negative'. Basic nutritional knowledge was needed to enable participants to be able to have a general concept as to what the label was trying to communicate.

Participants attempted to make use of and to analyse figures included in the traffic light panel. For example, Ruth found this information limiting because it only referred to the nutritional value per

portion. She explained that instead she needed to use the nutritional values per 100g on the back of the pack in order to be able to make decisions about which product to buy saying 'it doesn't tally from the traffic lights to the important information, which is like 100 grams'. William found the figures 'confusing' and Andrew needed more explanation in order to understand the nutritional values presented alongside the traffic light system and said:

'Oh, just before we finish on that just a quick point, sounds like a satire. If you add all the percentages up, when I was a lad in a previous century all the percentages would add up to 100%. A lot of these percentages when you add them up, they come nowhere near 100%, they're like ten or twenty percent. So, does that mean a lot of the material in there is rather like dark matter in the universe?' (Andrew)

While the traffic light colour system had the potential to make decisions simpler and straight forward without the need to undertake their own interpretation, the presence of the figures within the traffic light system limited the use of the system. It did not seem to help to make decisions between products and the figures were puzzling in that they did not appear to make sense.

Being able to interpret the figures recorded within the back of pack information was considered essential in order to assist with making decisions between products of the same type; to understand the nutritional value of the actual portion consumed; and to know how much carbohydrate was in a food. For example, Ruth described in the diary how she compared the nutritional values between different brands of breakfast cereals of the same type. Finding them the same nutritional value she was able to select the cheaper product.

However, in order to be able to use this information to interpret the nutritional values per portion consumed, participants needed to possess numeracy skills. While the traffic light system with a food labelled with three reds was an indication to Lisa to only have 'a small portion or a thin slice' it is still 'difficult to judge how much you are taking in'. Lisa explained that if people wanted to be very sure about how much they had eaten they would need to do extensive calculations. Lisa described herself as 'being reasonably comfortable with maths' and felt that it would be 'quite difficult for people' to do this detailed analysis. In her diary she included a calculation of the carbohydrate and sugar content of a slice of cake that she had eaten. The diary entry demonstrates the numeracy skills that would be needed to ensure people were aware as to how much they were eating.

Figure 18 Lisa's diary: Calculations

Day	Ouich calculation of fat and Carbolyde whate Fat Per 100g 70g Fat 9.89 7 × 9.8 = 684
I am fed up of food sitting in the findge - this leman has been in the pridge for about 2-3 weeks. I ate the last priece watching Great british bake Off, Weighed Tog.	$=6.86q$. Saturates $4.4q$ $\frac{7}{10} \times \frac{4.4 = 30.8}{10}$ $=3.8q$.
NUTRITIONAL INFORMATION	Carbohydrates 60.75 7 607=4245
OVEN 5 O YEARS IN THE BARRICE OVEN 5 O YEARS IN THE BARRICE LEMON SPONGE Serving sug serving sug	of which singus 40.5g 7 40.5=83:
Soft sponge filled with lemon curd and lemon flavoured buttercream	Not 900d!!!

I am fed up of food sitting in the fridge-this lemon cake has been in the fridge for about 2-3 weeks.

I ate the last piece watching Great British Bake Off. Weighed 70g

Quick calculation of fat and carbohydrate intake				
per 100g				
Fat	9.8g	=6.8g		
Saturates	4.4g	=3.8g		
Carbohydrates	60.7g	=42.49		
Of which sugars	40.5g	=28.35		
Not good!!!				

Lisa Diary entry
Top: Diary facsimile

Bottom: Diary transcription (Calculation not transcribed)

The label on the packet gives the suggested portion size of 38g, however Lisa decided to have 'the last piece' which weighed 70g. In order to be able to make decisions on what she could eat later in the day/week she needed to find out the nutritional value of the slice that she ate. Lisa undertook division and multiplication by hand to identify that there were 42.49g of carbohydrate and 28.35g of sugars in the slice of cake that she ate which using her own 'rule of thumb' she describes as being 'Not good'(Lisa- diary).

Numeracy skills were needed in order to be able to interpret the nutritional information on the back of the pack. This was used to compare against an individual's rule of thumb, what their own views about what they should be eating were, so that decisions about how much to eat and or what else to eat could be made.

Conclusion to food labels

The inclusion of examples of front of pack traffic light panels in many diaries suggest the tacit use of this information. When referring to using the system, participants highlighted the symbolism that the system held for them. However, for participants this symbolism focused on the use of red to denote that the food contained an unhealthy amount of an ingredient. To the participants the use of red on the food label meant that they should stop and think about whether to eat the food as it was dangerous to eat, and a better decision would be to not eat the food. The traffic light system, because it drew on everyday symbolism, was understood by many, was felt to have value and was considered to help participants to manage their diabetes. Participants felt that as people have a tacit understanding as to the meaning of the red-amber-green colour-coding system and how to apply it, the concept could be made use of more widely on the back of the packet nutritional information as this would help them understand the aspects that they were interested in. Few referred to the other colours used in the traffic light system – green or orange. The term was so frequent that it was tacitly assumed to refer to food that was unhealthy and so has become embedded in the day-to-day language about healthy and unhealthy foods and in information practice.

Participants' beliefs and nutritional knowledge influenced the way that they made use of the information on the food labels. Many appeared to focus on the amount of sugar in a food item even when the amount was found to be insignificant and had a general mistrust of food labels. They felt that they needed nutritional knowledge and numeracy skills in order to be able to make the most of the information as often the information was overwhelming and led to a feeling of confusion and

lack of confidence. Numeracy skills were needed in order to be able to interpret the nutrition information and apply it to their own 'rules of thumb'.

Food labels appeared to be an accessible and comprehensive source of nutrition information. However, the traffic light system was of limited value as it did not give participants the information they needed to know, and the back of pack information required nutritional knowledge and numeracy skills in order for it to be usable. Participants use of food labels was influenced by their beliefs about sugar and their dietary 'rules of thumb'.

5.3 Peers

The findings relating to peers often related to groups and/or meetings involving interaction with other people with T2DM. All participants referred to these as sources of nutrition information. There were three main types of groups or meetings referred to by participants. Support groups and support meetings (part of the informal support available to people with T2DM, lay led) and structured education (led by HCPs) (see introduction p. 8). Groups were those where the primary aim was to be able to share ideas and to talk to each other, usually consisting of smaller numbers than meetings. Meetings were sessions whose primary aim was for participants to learn about an aspect of T2DM management. These meetings were often larger in terms of the numbers attending.

Some participants had engaged in all three types of group or meeting as part of their information practice, while others had experience of one of these opportunities. Over half the participants were regular attenders at support groups, some attended support meetings and less than half had attended structured education sessions. There were occasional references to other formats of information practice involving peers such as a 'phone-in on diabetes' and a 'case study' about someone with T2DM (Ruth-diary) and Christopher and Frances referred in their diaries to an online 'forum' (where people could pose questions).

Other people's stories as an information practice material

A key aspect of peers acting as a material was the access to other people's stories and experiences. These were accessed through any source where there was engagement with or information about people with T2DM. The most usual way that other people's experiences was accessed was through groups. For example, Victoria said that 'a lot of people have got other ideas and things they have come across'; Oscar spoke in his interview and wrote in his diary about 'other people in the group'

and their 'experiences' being a source of information; and Helen said 'not just the speakers, it's other people give input' into the group discussions sharing their experience and ideas in the group.

However, one participant also spoke about hearing about experiences through broadcast media and through online forums. For example, Ruth heard about how one man had lost weight through changing his food, lifestyle and exercise. She likened it to her own experience of weight loss and wrote in her diary that she was 'inspired' by this and said in her interview that it was 'a great booster to me'. In this way it seemed that whatever the format of receiving the nutrition information, the experiences of peers and their ideas were of great interest and support to other people with T2DM.

The source was felt to be more powerful, to have more value when the participants felt that there was a similarity between themselves and others. For example Jennifer wrote in her diary about attending her first support group 'meeting other like [minded] people and listening to their stories'; Danielle who attended a structured education session with her husband Christopher spoke about how within the group she found it reassuring that there were 'couples ...like us where one had got it and the other one hadn't'; Frances spoke about how she had engaged with an online forum saying 'it's the forum side of it I like. And it's everybody else going through the same process'. Conversely, she spoke of how she felt she was not like the other participants in the structured education session she attended. The other participants had a 'different attitude' from her and did not appear to want to learn or to engage. This impacted on her engagement in the group and her overall learning. The information practice involving peers had two components. It seemed that for the information to be valued and trusted the participants felt that it needed to be of benefit to themselves. This belief as to the potential value of the source was enhanced when the information was seen to be from people like themselves, aimed at people like themselves, at the same stage of the disease and with the same attitude of wanting to learn about how to manage T2DM.

The availability of nutrition information as a material

Structured education sessions were a valued source of information, however, a number noted the strict criteria applied to the availability of structured education sessions meant that they had not personally been referred. Several participants had been excluded from being able to attend these because the sessions were only made available to those who were newly diagnosed with T2DM. For some though not being offered the opportunity remained a mystery. Gary said:

'...whether it's something they forgot to mention it to me or I forgot to mention it to others or whether its financial pressures in their budget and they can't afford to spend that money on somebody or what it is, but there are some of us who've been offered it and some who haven't.' (Gary)

While comparing the relative value of the different formats of information practice involving peers the time spent during these sessions was also discussed and compared to other sources of information such as HCPs. Participants were aware of the limitations to the time available for the GP to discuss nutrition during the 'once a year diabetes review', with the dietitian who 'you only see...for a twenty-minute half an hour slot...then you're gone for another year' and indeed the complete lack of availability of advice in some GP practices, being told 'we don't do that anymore' (Jennifer). However, the peer sessions were also seen to have limitations in the time available. For example, the structured education sessions where 'there's no backup to it' (Theresa) was considered a limitation and so having a regular 'monthly meetup' (Ruth) in the support group or 'with the dietitian [going] once a month' (Helen) were preferable situations and 'probably better' than the one-off structured education sessions. There was potential for the structured education sessions to be a valued source of information in comparison to other types of information where the opportunity to explore how to manage T2DM was not limited by time and frequency. However, the lack of availability and the time and frequency of the structured education sessions meant that it was devalued as a source of information practice for people with T2DM.

For those who were regular attenders at the support groups and especially those who were involved in the organisation of these, the topic of funding was a common discussion in the interviews. The support groups from which the participants in this study had been recruited had been operating with funding from Diabetes UK, but this was to come to an end and after that groups would be 'out on our own' (William) and need to manage without funding. Although individual members could pay for the hall Ruth said, 'it probably would not happen'. The long-term availability of the support groups was not guaranteed and although the sessions were 'fronted' by Diabetes UK their potential as an ongoing resource relied on the individual members of the groups and hence may limit their long-term viability as a source of information.

Information practice involving peers appeared to be a source of more readily available information than that involving information from HCPs such as GPs, practice nurses and dietitians. However, some interactions involving peers as in the structured education sessions were felt to be limiting in

that they were only available as one-off sessions and were only available to those that met specific criteria (i.e. being newly diagnosed with T2DM). The opportunity to see an HCP such as a dietitian on a regular basis was preferable to the one-off structured education sessions. Overall, the value was in being able to have regular opportunities to talk about how to manage T2DM and this overrode single consultations with an HCP and one-off attendance at a structured education session. There was apprehension about the time limited resources to continue to run peer support group sessions. Should the Diabetes UK funding come to an end this would suggest that these valued sessions would no longer be available as a source of information. The concerns about accessibility and availability of information practice involving peers suggest that information practice with peers cannot be relied on long term for nutrition information practice for people with T2DM.

A secure setting

The way that the information and support involving peers was experienced was considered an important aspect to people with T2DM. Ensuring that the venue and setting enabled participants to feel 'comfortable' (Oscar), facilitating interaction, avoiding situations where there was 'cliquish chat' (Christopher) and where 'somebody gives a lecture and you go away...[without having]...the chance to find out if you have enjoyed it or not' (Gary) were important organisational aspects. Participants valued information practice involving peers when the setting and format ensured ongoing engagement in the process. One of the aspects that was identified in promoting engagement was the skills and personality of the person leading the session. For example, having skills in leadership and being 'able to keep the group running' (Matthew); being able to 'inspire others' (Victoria), being 'keen' and 'willing to help other people' (Helen) were attributes identified by the participants as adding value to the experience of the information practice.

The way that the source of information is experienced was noted by participants as being fundamental in whether they were able to engage. Managing the setting that facilitated engagement and a feeling of security to encourage participants to talk to each other was important. Using positive language and terms that people could understand and putting across a confident and optimistic persona when delivering and leading sessions were all attributes of the information practice that were also valued by participants.

The meaning of nutrition information practice with peers

The meaning behind nutrition information practice with peers related to the impact that the practice had on participants both in terms of the value that being able to talk about food brought and the

social communication with others like themselves. Gary explained that diet was the 'top subject that people want to talk about' in a group setting. Some participants referred to food information that they had learned from the information practice. For example: 'food groups' and 'food value' (Penelope); Danielle said she and Christopher learned 'about the different foods you should be eating and giving advice on shopping and cooking'; Lisa said she learned about 'portion sizes and things like that'; and Helen and Penelope learned about 'what not to eat'.

While these participants verbalised the food topics that they had learned about, a number did not, instead they spoke about the value of engaging with peers to help them to live with T2DM. Participants did not verbalise specific information gleaned from peers instead they referred to situations where they had learned new information or had achieved a greater understanding as to how to cope with T2DM.

For example, Helen said that the support group 'certainly helps' and that through the discussions she had 'picked up a lot of ...things from other people'; Oscar referred to 'picking up suggestions'; Ruth referred to 'fascinating information' that they were advised that 'there's some new writing on that'. Victoria said 'you can try different foods you would not have thought about' and Edward explained that his experience from attending groups was that 'you learn something that you did not know previously'. Participants said they gained an 'understand[ing] more of what to do' (Jennifer); 'understanding more about the condition' and 'seeing it from other people's perspective as well as your own' (Gary). Although the concept of learning from others appeared to be of value, this was not always the case. For example, Christopher said 'it can be depressing... to read [about] other people's problems' within online forums and Yvonne said she found the support group sessions 'boring' hearing about other people's experiences over the previous month.

While the general concepts of ideas and new suggestions were useful, people with T2DM also needed to understand how to work those ideas into their day-to-day lives. The information practice of engaging with peers giving the opportunity to ask questions of others with T2DM and share ideas yielded the process of how to incorporate those ideas. For example, Ruth told me about two experiences she had at the support group session where the exchange in ideas had led to her being able to incorporate ideas about portion sizes and for others in the group how to increase their consumption of vegetables:

"...obviously cheeses are not good for you and different types of cheeses, and then they said about what size you should be eating, rather than going to a lump, chunk, it's cutting it off, grating it up and then eating it. They mentioned this matchbox size and I just thought "What does that look like? Let me do that and let me see." And yeah, to actually get an idea of size and quantities.'

"...and you are just going, "Well, did you not think of maybe putting some carrots in there?" "I don't like carrots." "Yeah, but if you mash them up, and mix them up with the potatoes..."

You know, just giving each other ideas.' (Ruth)

In both these examples the opportunity to discuss how to follow participants' 'rules of thumb' of controlling their portion sizes and increasing their intake of vegetables were crucial in being able to apply the information to tacit and mundane aspects of everyday lives. In the first example Ruth was aware that eating a large portion of cheese was not healthy for her but was not sure how much she could eat and how to keep to that amount. Through discussion with the other participants in the support group she was able to visualise the portion size ('matchbox size' (diary)) and how to make the portion size look enough to satisfy her appetite (by 'grating it up'). In the second example Ruth explains how her interaction with others helped to show those who are not keen on vegetables how they could include more into their diets without noticing (by mashing carrots up with mashed potatoes). The specific advice of eating more or less of a food needed contextualisation in people's day-to-day lives and the opportunity to ask others and to share ideas with others who had experienced following the specific advice enabled participants to be able to apply the information to their own food practices.

There were times in the discussions with the participants when it appeared that the idea of learning was not the main benefit that participants achieved from the group. Instead, it was the atmosphere, familiarity and friendship experienced when attending the group that gave it meaning. For example, Ruth said 'you are like friends' and this enabled the discussions about how to implement the new information into their food practices. Oscar explained how it was important to feel 'comfortable' with people. On the other hand, not experiencing friendship within a group can impact on the experience and value. Yvonne had been attending a group with a friend but when they were not able to attend any more Yvonne said that then she 'didn't really get anything out of it'. While atmosphere, familiarity and friendship appeared to facilitate learning and promote meaning and a

feeling of trust amongst participants, when this was absent through the group having a different attitude or through not developing friendships this appeared to limit the experience and meaning.

While participants learned about specific types of foods to eat and how much to eat from peers it seemed that what was equally of value were the aspects of how to incorporate this information into their daily lives. The interaction with peers filled the gap of how to apply the nutritional advice, hearing how others had succeeded would help them master the skill of living with T2DM. However, interaction with peers had an added impact that of the potential for friendships and when present this was an enabler to the nutrition information practice involving peers.

The need to be competent in social interactions and collaboration

A key aspect of the information practices involving peers were the social and dynamic acts of talking, conversation and discussion. These communication activities were referred to by several participants when talking about their involvement with peers especially those where participants took part in group sessions, either structured education or in support groups. The practices of 'meeting' (Ruth, Jennifer) face to face with others who had T2DM in order to exchange ideas and 'talking' (Ruth, Gary, Oscar) with each other were emphasised as being important aspects of information practice. Talking would lead to a 'conversation' (William) which would lead to a discussion that enabled understanding how others lived with T2DM. For example, Helen said 'like somebody might throw something in and we would have a conversation...I've learned quite a lot from different people...'.

Participants did not always need to be involved in the two-way process of communication in being engaged in information practice. For some the practice involved reading about and 'listening to their stories' in order to understand 'what to do' (Jennifer-diary). Indeed, William was aware of the importance of listening to others in the group he led. He made sure that only one person spoke at a time at the meeting that he ran especially when there were a lot of people, 'so they can hear what that person is saying'. He explained to the group that "it might be important to you"'.

The process of social interaction using communication skills was key in ensuring that participants understood each other and their individual thoughts about living with T2DM. This enabled participants to find out about how others lived with T2DM, giving another perspective on how to live with T2DM and enabling participants to consider how this may be applied to the way that they already lived with T2DM and their own 'rule of thumb'.

Talking and conversations went beyond finding out about how others coped with T2DM to the practice of collaboration, that is, engaging with each other and sharing ideas on how to live with T2DM. Social interaction went beyond hearing others' perspectives, to working with each other on how these ideas about how to live with T2DM might be applied to both themselves and the other people. Participants spoke of 'involving people' (Gary) to enable 'asking questions' (Helen), exchanging 'ideas', 'picking up suggestions' and gleaning 'as much information as you can' (Oscar) in order to learn and understand how others live with T2DM and to be able to apply it to themselves. For example, Gary said:

'And it's the relationship thing, and we can understand if others ask the same questions it shows that we're not stupid, we just have not had things explained properly to us. It gives us better opportunity to help ourselves as well as others.' (Gary)

It was not just talking that was important in the information practice but also the practice of sharing and exchanging ideas and thoughts that was key in understanding and learning how the experiences of others with T2DM might be applied to their own lives with T2DM and their 'rule of thumb'.

For the practice of sharing and exchanging ideas to occur however, meant that the participant needed to be willing to engage and communicate with others about their T2DM and to believe that the information practice of engaging with peers would be of benefit to them. The readiness of the participants in this study to talk to each other, to listen, to exchange ideas in order to take 'on board what they've said' (Ruth), to be 'mentally receptive' (Matthew) and 'ready' (Frances), appeared to be an embodied asset, an embodied disposition. Not being able to come to a meeting because of poor health (Susan) or lack of transport (Matthew) were structural reasons for not engaging in these learning opportunities. These were different from embodied dispositions that made engaging with peers difficult. Not wanting to come to a meeting because 'that's not their thing' (Matthew); not engaging in the information practice, 'not interested in it' (Frances); being 'complacent about their diabetes' (Christopher) and 'trying to get people to respond' (Christopher) on a diabetes forum, were experiences that underlined to the participants that not everyone had the embodied disposition that would enable them to undertake information practice with peers. It may be that they do not enjoy engaging with other people in a group setting, that they were indifferent about engaging with others in order to understand how to manage their T2DM and about their diabetes overall. They perhaps could not see the need for this type of information practice and did not believe the practice would benefit them.

Collaborating with peers went further than finding out what to do. The process was two-way with exchanging ideas about each other's 'rule of thumb' and developing ideas between each other. For this to occur participants needed to possess the disposition of being interested in and willing to engage and share ideas. Participants felt that this disposition of being willing to engage with peers was not something that everyone naturally possesses. They suggested that for these people it may be that the information practice with peers was not their preferred way of finding out how to manage their T2DM; they may be indifferent to the information practice and or to self-managing their diabetes.

Conclusion to peers

Participants engaged with a range of settings in order to undertake information practice with peers: structured education, support groups, support meetings but also online forums and listening to radio phone-ins. However, the availability of these valuable materials as sources of information was not secure. Structured education was not available to many participants as it was rationed and normally only offered to those who were newly diagnosed. While some attended support meetings, there were concerns about the ongoing availability of support groups.

The commonality in the meaning behind accessing these settings was hearing about the experiences of others with T2DM in order to learn to live with T2DM. However, when the setting was secure, and friendships were developed such as in a support group, this enabled collaboration through simple conversations. Participants were able to share ideas and to learn how to apply the experiences of others to their own lives. These ideas were tacit, there was a focus on processes, that is how to go about eating for T2DM as opposed to giving specifics of types of foods and how much to eat.

However, in order to be able to exchange ideas and each other's 'rules of thumb' and to develop relationships, participants needed to engage in these conversations, that is to be attuned, open and responsive to the conversations with peers. Participants saw these competencies as being an asset which those who appeared to be closed to suggestions as to how to live with T2DM lacked. Not only did participants feel that there was a need to be open to ideas, they also needed to understand the importance of being able to make their own decisions. So, in this way people with T2DM need to possess the competency for communication and collaboration in order to find new ideas and to make use of them.

The value of structured education and support groups was not always realised. For some the makeup of the group prevented interaction and the concept of sharing experiences was not always found to be beneficial. While the idea of sharing ideas in how to live with T2DM seems to make sense, not everyone is attuned and ready to hear about how others are managing or coping. In some cases, this could cause distress.

5.4 Summary

In this chapter by using practice theory and the components of materials, meaning and competencies I have sought to explore the information practices involving food labels and peers as the two most common sources of information accessed and utilised by the participants. Using these components has enabled the identification of the positive aspects, the different value to participants and their shortcomings of these two sources.

While food labels appear to be the most readily available source of information their value appeared to be limited to assisting participants to identify foods that would be dangerous for them to eat. The traffic light system resulted in an over emphasis on foods that had a red colour on their label, with little attention paid to the green and amber colours that may indicate foods that participants could eat. In contrast the value of support groups especially was highlighted for their ability to help participants to learn how to live with T2DM. Through collaboration and sharing of ideas participants were able to learn how to apply processes to their own lives.

The value of food labels to people with T2DM is limited by the variation in format in food labels, a lack of nutritional knowledge amongst people with T2DM, a lack of numeracy skills, the presence of embodied beliefs and 'rules of thumb' about the way they manage their diabetes. These factors are coupled with the standardisation of the information on the food labels for the general population as opposed to those with T2DM with varying nutritional needs. These limitations mean that people with T2DM either don't use the food labels or are unable to use the food labels to help them make decisions and when they do use them, they focus on interpreting aspects of labels which have less of an impact on the management of T2DM. The use of food labels appeared to make people who had been living with T2DM for some time question their confidence in being able to manage their T2DM and those newly diagnosed to consider if they would ever be able to understand what to do.

In contrast to food labels, the interaction with peers appears to have a greater value, although the specific learning of what to eat is not easily identified it seems that the interaction with others who

have T2DM and sharing their 'rules of thumb' help them understand the tacit mundane aspects of how to live with T2DM and provided a source of comfort and reassurance. Although most participants were recruited from group settings which may in turn have emphasised the value of the information practice, some limitations were identified. These limitations included the ability to engage in peer opportunities and the long-term availability of these opportunities. Structured education was rationed to those who were newly diagnosed, and the long-term availability of support groups was under question. However, participants felt that the format of engaging with peers may not be for everyone and that in order to be able to undertake the information practice, participants needed to possess the embodied dispositions of believing that engaging with others would help them to manage their T2DM and of being willing and ready to engage in the process.

For both sources, however, skills attributes and dispositions were needed in order to be able to make the most of these sources. Numeracy skills were needed in order to be able to interpret food labels and a disposition, a willingness to interact with others was needed to be able to make the most use of the peer settings. For food labels the figures on the front of pack food labels did not appear to make sense and extensive numeracy skills were needed and used in order to be able to make use of the back of pack information. However even with numeracy skills present the amount of information often led participants to feel overwhelmed and confused. While the sharing of ideas appeared to be a powerful experience in support groups if the setting did not make participants feel secure and comfortable participants disengaged from the group. Both sources required the presence of skills and the willingness to use these skills in order to engage with the information, without these skills the value of the information would not be realised. Crucially without these skills, the interaction with the source had the potential to cause harm in loss of confidence in being able to self-manage.

The information practice involving both food labels and peers was influenced by embodied aspects. The interaction with food labels was influenced by embodied knowledge and beliefs and about sugar, and the engagement with peers was influenced by the embodied disposition that the practice would help them manage their T2DM. However, the information practice with both sources was influenced by their individual 'rule of thumb' and the embodied disposition of being ready to engage in information practice. Embodied knowledge, beliefs and dispositions influence the information practice of people with T2DM, although the causes and influences of the embodied aspects are unclear.

This chapter has explored the information practices of the participants by using two commonly accessed but very different sources of information. The process has identified the challenges that the participants faced in being able to apply this information to their own lives. The next chapter explores the nutrition information practices of two participants at different stages of living with diabetes in order to understand nutrition information practice at an individual level and to examine further the potential causes and influences of the embodied aspects of nutrition information practice.

6 Chapter 6: The influence of embodiment of T2DM on nutrition information practices

In order to understand information practice at an individual level and to explore what influences the embodied aspects of nutrition information practice identified in the previous chapter, this chapter explores the nutrition information practices of two participants in more detail. The elements of practice theory (meaning, materials, and competencies) are identified. However, the chapter also seeks to demonstrate how the process of embodiment impacts on information practices.

Two participants from the study have been selected as cases to present in detail to illustrate the impact of embodied diabetes on information practices. Theresa has been selected as someone who is early on in her diagnosis and is learning how to live with T2DM, while Isobel was someone who has had diabetes for approximately 20 years and describes herself as a *'researcher'* at heart, wanting to assist others in managing their T2DM. I start with Theresa and follow her case with Isobel.

6.1 Theresa: an example of the embodiment of early diabetes

Theresa was early on in her diabetes diagnosis and had struggled to come to terms with and to embody the diagnosis. In this section the researcher aims to show how food practices, embodied food preferences and dispositions coupled with beliefs about diabetes and experiences at the time of diagnosis influenced the embodiment of diabetes and nutrition information practices.

At the time of the study, Theresa was in her early 50s and had been diagnosed with T2DM for one year. She also suffered from blood clots in her leg and had a nut allergy. She was on medications to manage her diabetes and to prevent further blood clots in her leg. She lived with her husband, son, daughter and her daughter's boyfriend; she was a security guard, often working night shifts. Theresa cooks for her husband and son, but her daughter and her daughter's boyfriend cook for themselves. The food available in the house was supplemented by vegetables from an allotment which Theresa gardens. Her diary reports that she had harvested curly kale, Jerusalem artichokes and Brussels sprouts from her allotment. Theresa does not like shopping and buys most of the food online along with a regular delivery of a vegetable box which helps to supplement the vegetable supply over the winter months when there is less from the allotment. Theresa's diary included the festive period of Christmas starting her diary in the first week of December and completing it in the first week of January.

Embodying diabetes

This section introduces the way that Theresa embodied her diabetes and how this influenced her information practice. Theresa's narrative began with an explanation of her diabetes diagnosis. There had been a six-month delay between her being tested and her finding out that she had the condition. This was partly due to Theresa not following up the results, assuming that she would be told if she had diabetes and denying to herself that she had diabetes as she describes herself as being 'a bit of an ostrich when it comes to being ill'. Although others in Theresa's family had T2DM and she thought she probably did have the condition as she linked the feeling that her 'lips were dry' with having diabetes, the idea of having it frightened her. Theresa describes the shock she felt at finding out that she had diabetes, how after finding out she 'sat and cried, because I just didn't realise'. Between receiving the diagnosis and seeing the diabetes nurse Theresa remained in shock and became worried about what would happen. She said 'by [the time I saw the diabetes nurse] I was up in the fairies, thinking of all the worst things that can happen to you'.

When Theresa went to see the diabetes nurse, the nurse gave her a book about diabetes. However, even though Theresa was aware of diabetes and had experienced family members being diagnosed with it, the fear of the unknown prevented her from being able to take in what was written in the book. She describes a feeling 'like someone had hit me over the head with something, and I was trying to read [the] book, that just didn't want to go in there'. The fear of the diabetes appeared to be a barrier that prevented her from coming to terms with having diabetes and from being able to comprehend the information in the book.

While this barrier was there, Theresa was not able to read the book, was not able to undertake information practice and so was unable to move forwards in finding out about diabetes. After a while Theresa was able to read the book saying, 'so it did take me a while to actually, I did read it, and I just thought, 'Oh my god,'. Theresa did not say how long it took for her to read the book and to start to come to terms with the diagnosis. However, she talks about a gradual change, an understanding in the importance of taking her medications and then noticing a diabetes support group session advertised at her local supermarket. Theresa had shifted from being frightened and upset about her condition to being ready to learn about diabetes. She was able to explore living with diabetes further such that information practice had become part of her habitual embodied day-to-day practices. Theresa's information practice was influenced by her coming to terms with the diabetes. This process of embodying diabetes did not move in clear stages, rather the process was

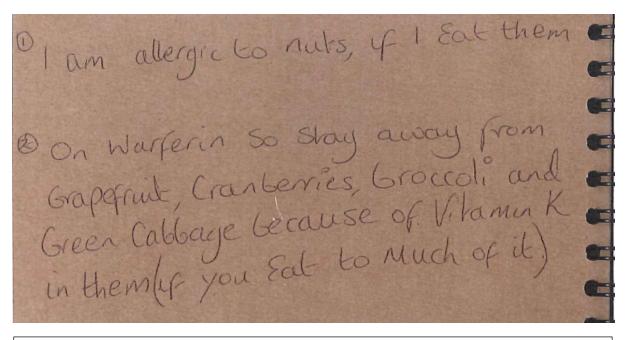
imperceptible and was key in enabling Theresa to self-manage and to undertake information practice. The embodied diabetes acted like a conduit enabling her information practice.

Theresa's 'rules of thumb' (meaning)

Once accepted, Theresa's diabetes practices became part of her alongside her other day-to-day practices such as ensuring her family were looked after and managing her other health conditions and influenced her 'rules of thumb'. The health conditions influenced the foods that she could eat. They meant that she needed to avoid specific fruit and vegetables. She explains at the start of the diary that she is on medication (warfarin) which means that she needs to restrict the consumption of some fruit and vegetables ¹⁰, and to avoid eating nuts as she is allergic to them.

¹⁰ NHS guidance on what to eat with warfarin recommends small amounts of green leafy veg and avoiding grapefruit and cranberry juice. This is the link: https://www.nhs.uk/medicines/warfarin/

Figure 19 Theresa's diary: Influence of medical conditions on food choice



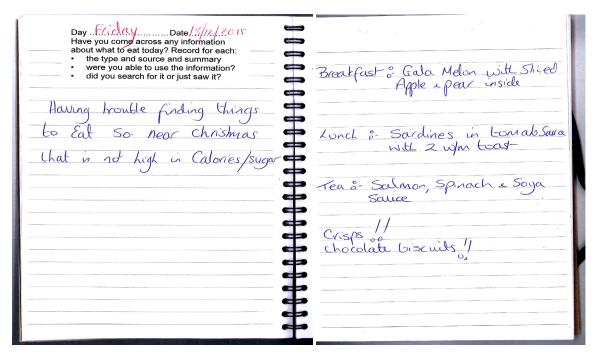
- 1. I am allergic to nuts, if I Eat them
- 2. On Warfarin so stay away from Grapefruit, Cranberries, broccoli and Green Cabbage because of Vitamin K in them (if you Eat too much of it)

Top: Theresa Diary Facsimile:

Bottom: Theresa Diary Transcription

The diabetes influenced her dietary 'rules of thumb', and Theresa often listed in her diary what she had eaten during the day to emphasise her adapted 'rule of thumb' as to what was now healthy for her to eat with her diabetes. For example, in this section below Theresa notes how difficult it is to find foods that meet her 'rule of thumb' i.e. foods that are not high in fat, sugar and energy (these foods being scarce during the Christmas period). This entry is followed by a day's food record that appears to emphasise the consumption of fruit and vegetables and oily fish (part of her rule of thumb). The subsequent consumption of foods high in energy and sugar (crisps and biscuits) are highlighted suggesting that these foods were not part of her 'rule of thumb'.

Figure 20 Theresa's diary: Difficulties with food choice over the Christmas period



Having trouble finding things to eat so near Christmas that is not high in calories/sugar Breakfast: Gala Melon with sliced
Apple & pear inside

Lunch: Sardines in tomato sauce

with 2 w/m toast

Tea:- Salmon, spinach & soya

Sauce

Crisps!!

Chocolate biscuits!!

Top: Theresa diary facsimile

Bottom: Theresa diary transcription

I have outlined the experiences that impacted on Theresa's ability to come to terms with and to embody her diabetes. Once the diabetes was embodied, Theresa was able to undertake information practices, however these were impacted on by other aspects of her life such as looking after her family and her additional health conditions. The embodied diabetes was not a discreet embodiment but instead became part of her overall self, influencing how she lived her daily life, impacting and changing her dietary 'rules of thumb'.

Theresa's nutrition information practice

The embodiment of living with health conditions give a personal context to how Theresa's information practices changed once the diabetes had been embodied. The process of embodying diabetes and being ready to face it and to self-manage the condition enabled Theresa to undertake nutrition information practices that became habitual day-to-day practices. In this section I explore the practices that formed the meanings, competencies and materiality behind Theresa's information practices, starting with meanings.

Meaning

Theresa was not able to undertake information practice until she had accepted and embodied the diabetes diagnosis as part of her identity. Once she had embodied diabetes she was able to proactively undertake information practice. Early in the embodiment process she started to read the book on diabetes that the nurse gave her, but she took her time over it. Once she had accepted the diabetes, her aspiration to self-manage her diabetes meant that she became aware of other sources of information around her that were relevant to her diabetes. She had appeared to have accepted the diabetes when she noticed the advert for the support group. So, by this point it was clear to her that her information practice had begun. T2DM information practice was enabled now as she had accepted and embodied the diabetes diagnosis.

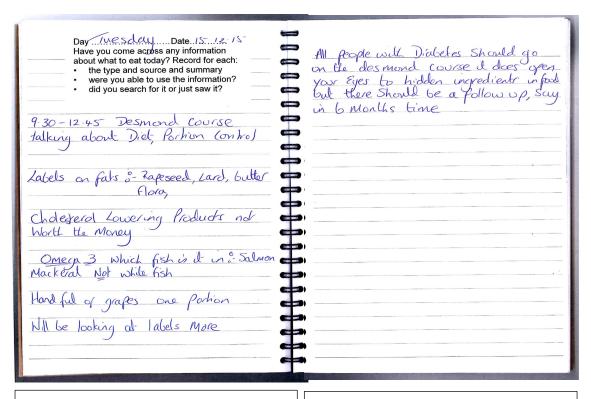
Further examples of this process of embodiment and its impact on information practice is illustrated by Theresa's awareness of and interest in public information messages as they seem to have relevancy to her. One example was the public information message about the Government intention to reduce the amount of hidden sugars in foods, and she writes in her diary 'Government want to Cut down on hidden Sugars - on the Radio'. This held resonance for Theresa because she was starting to interpret food labels and the hidden sugar values in foods in light of managing her condition. She said in her interview '... and it's true, because the sugars are hidden, aren't they? And you don't

realise how much sugars are in things until you start reading the labels, and it is just amazing'. In this way Theresa's acceptance and embodiment of her diabetes had given meaning to her information practice. Once Theresa had accepted and embodied her diabetes, she was able to undertake nutrition information practice.

During the diary period Theresa was still learning about diabetes and developing her 'rules of thumb' for managing her condition. She writes in her diary on Christmas Eve that she is 'finding it hard to control [the diabetes] just at the moment as this is my first Christmas with it, hopefully I will understand it more next year'. And then in the New Year she writes with new resolve: 'Start of new diet, New Exercise and this year my leg is going to help me, not control me!! So lots more exercise and lose weight to get rid of diabetes all together and come down on pills'. Theresa's diary is an illustration of how she went about trying to achieve her 'rules of thumb' alongside her other health conditions and family life. However, the cultural festivities of Christmas made it especially difficult for her to follow her 'rules of thumb' because of the types of foods that were available.

The meaning to Theresa's information practice was also influenced by her disposition and her preferences for the format for information practice. The importance of being able to develop friendships and being able share her approach to self-management of her diabetes with others. Theresa identified group discussions with peers, hearing about the experiences of others as being beneficial to her, having attended regular meetings with a support group. During the diary period Theresa also attended a structured education session to which she had been referred and recorded in her diary a list of the topics that she had learnt about. However, unlike the regular support group, the impact on her learning and feeling confident with managing her diabetes through learning alongside others and being with others in a group was limited as there was no follow up to the structured education session.

Figure 21 Theresa's diary: Impact of structured education



9.30-12.45 Desmond course Talking about Diet, Portion control

Labels on fats:-Rapeseed, Lard, butter, flora

Cholesterol lowering products not worth the Money

Omega 3 which fish is it in:-Salmon Mackerel Not white fish

handful of grapes one portion

Will be looking at labels more

All people with Diabetes should go on the desmond course it does open your eyes to hidden ingredients in food but there should be a follow up, say in 6 months time

Top: Theresa diary facsimile

Bottom: Theresa diary transcription

Materials

Theresa had particularly engaged with peers in the group setting; for her they were a key source of information. She spoke about the companionship of 'having everybody in a group' where she was able to develop bonds enabling her to learn more. However, the diary entry above suggests that Theresa expected there to be a follow up to the structured education session to enable shared experiences. She explained in her interview:

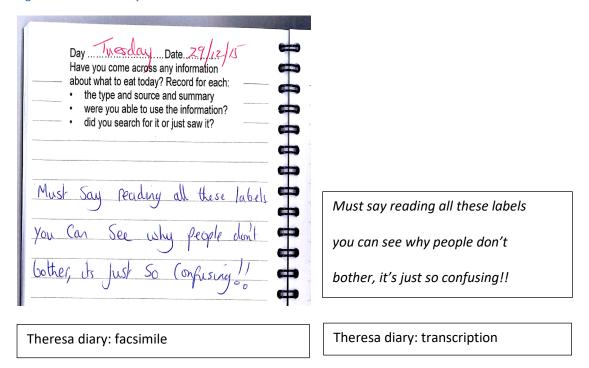
'because there were lots of people there that were new to it, just like me, and after a while you think, 'Am I doing the right thing? Is this the right thing, or should I be doing something else?...so you go on the course, and then you're just dropped from a big height, which is really sad because they teach you lots of things and make you look at things, but then after that you're on your own, and it's quite sad'.

Although the specific guidance was valued, it was the ability to return to the teaching from the session to see how others had managed that was important to her. Also, the relationships that Theresa had developed with people who were at a similar stage of their diabetes to her that made the impact of the structured education session on her ability to self-manage so powerful. This emotion that she felt when there were not going to be any follow up sessions limited the meaning that she felt that she was able to obtain from the structured education. Theresa found information practice that involved learning from peers most useful, how they were managing their diabetes but also to feel supported by peers through the process of developing friendships. The information that Theresa gained from the structured education session she attended was limited by lack of a followup session. This would have enabled her to find out from others how they were managing but would also have helped her to feel supported in an environment of friendship which would have enhanced her learning. However, the diary entry also suggests that Theresa did not expect to be able to undertake all of the strategies in managing T2DM straightaway. Instead, she understood the time it would take to incorporate her new learning into her food practices and her 'rule of thumb' in how she manages her T2DM. Theresa comments that it would be beneficial for the group members to meet up not in a few days but in 6 months' time.

Food labels were a tangible source of information (i.e. a thing) accessed by Theresa. These were used to make decisions as to whether to purchase a product or not. As discussed above Theresa had sufficient skills to identify specific aspects on food labels in order to make decisions about whether to buy a food. However, Theresa also identified their limitations not just to herself but to others. For

example, in the diary section below Theresa explains that people with T2DM may be trying to use food labels to make day-to-day decisions about what to eat, but as the information is so overwhelming, she wonders how people can make use of them.

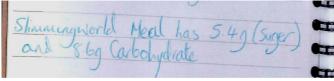
Figure 22 Theresa's diary: Limitations of food labels



Other food labels are also included in the diary. A food label from the marshmallows which her son eats was included to emphasise the high level of sugar in the food item and from the 'slimming world' sweet potato curry to emphasise the hidden sugars. While other food labels were included as a way of identifying that she was eating more of these foods (for example: oranges). Included below is one of these examples, the sweet potato curry as an indication of the use of food labels in nutrition information practice. Theresa emphasises her knowledge and understanding that the food has 5.4g of hidden sugar and 8.6g of carbohydrate but does not equate these calculations to how much she would be consuming in a portion and whether she feels this amount is acceptable, high or low.

Figure 23 Theresa's diary: Analysis of the back of pack nutrition information





Slimming World Meal has 5.4g (sugar) and 8.6g Carbohydrate



Theresa diary clockwise from left: Front of pack food label, facsimile of diary entry, diary entry transcription, back of pack food label facsimile.

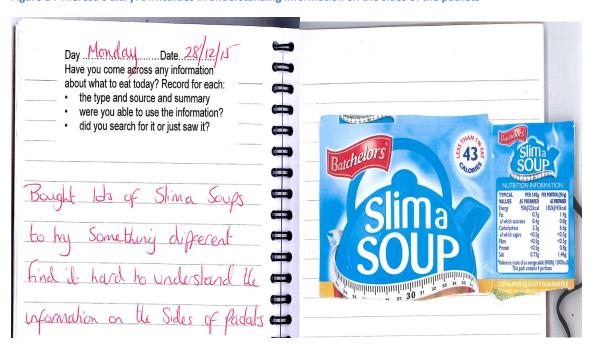
Competency in the form of embodied knowledge and skills

For Theresa being able to engage with other group members in the structured education session she attended was a key reason why this information practice had an impact on her ability to self-manage. The information practice impacted on her embodied diabetes and led to her development of knowledge and know-how in self-management. Theresa identified that she had learned about the importance of looking at food labels during the structured education session. Furthermore, she explains that she sees food in a different light, suggesting the development of a skill, and embodied knowledge to undertake information practice and to be able to identify foods that may not be healthy. Theresa explained that she looks at food 'differently' now. Having purchased a tin of curried baked beans assuming that they would not be high in sugar and so be healthy for her, thinking "... it's just curry powder and beans,". However, once she got home and looked at the label, she realised that what was in the food was 'not quite what it says' i.e. not quite what was suggested on the tin and was much higher in sugar that she thought. Theresa explained her change in approach, she said 'before, I would have just picked up a tin and put it in the shopping, where now I look at it and then think, 'God, yuck,' and usually put it back'.

Now the information practice has become tacit as she automatically checks food labels whilst shopping and uses her now embodied knowledge to ensure that she does not buy the wrong type of food. Having interpreted that the food did not meet her 'rule of thumb' (indeed the food was so outside her 'rule of thumb' that she found it repellent (meaning), she chose to not purchase the food).

Although Theresa was able to use her skills in being able to identify from a food label when a food was not healthy for her, she also showed that looking at food labels was challenging for her. In her diary she made several entries about food labels that suggest that she did not always have the skills to interpret the labels. Theresa includes the sample of the food label from the soups that she had purchased as a way of illustrating their complex and indecipherable nature to her.

Figure 24 Theresa's diary: Difficulties in understanding information on the sides of the packets



Bought lots of Slima Soups to try something different find it hard to understand the information on the sides of the packets

Top: Theresa diary facsimile

Bottom: Theresa diary transcription

Theresa had the knowledge and understanding to know that she should be looking at food labels as part of managing T2DM and was able to identify issues with some foods. However, she found that food labels were difficult to use and particularly the information on the side of the packet where the nutritional information and ingredients were recorded. There is a feeling of exasperation in the tone of the diary entry. It seems that Theresa has tried very hard to look at food labels and to interpret them.

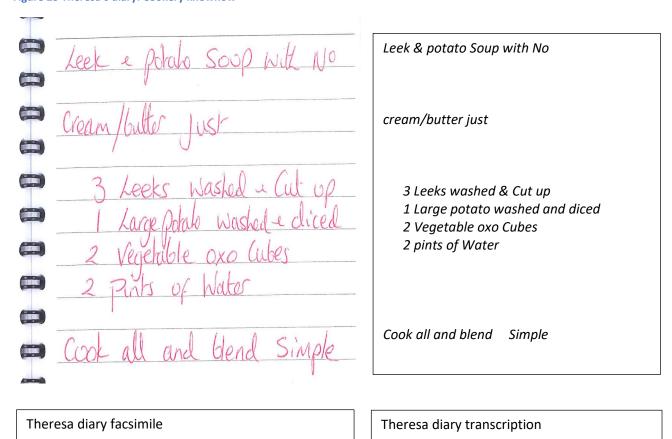
The embodied competencies of cookery know-how and recipes

Theresa accessed the internet, specific websites, recipes and recipe books, television and newspapers for information about what to eat. She proactively searched for recipes for diabetes on the internet, using specific websites and visited the library to obtain recipe books aimed at people with diabetes and took note of relevant information about what to eat from the television and when

reading newspapers. However, Theresa reported, especially during the festive Christmas period (when she completed her diary) that the value of these sources was varied. Some emphasised foods and ingredients that did not meet her 'rule of thumb' and did not appear to be relevant to people with T2DM so their value was limited while others helped her to be able to self-manage. For example, in her diary she refers to television adverts as being all about 'goose fat, double cream and butter'. While she describes information from charitable diabetes organisations such as the Diabetes UK website as being 'brilliant' as it gave a lot of relevant ideas for her to try especially during this festive period. Theresa records how she looked online for 'diabetic information' and 'diabetic recipes', finding that there was limited information available. Theresa searched (competency) for suitable recipes online and in recipe books. However, she said in her interview 'I just didn't find any of them interesting, or tempting, so I just turned [the computer] off'. Recipes that were suitable for people with T2DM appeared to be in short supply and this restricted Theresa's information practice in searching for 'Diabetic recipes'. This led her to use her cookery know-how in adapting recipes that she already used to meet her dietary 'rules of thumb'.

Theresa used her competencies of embodied knowledge and cookery know-how to identify that the recipes in her search were no different from normal recipes. Although Theresa notes that the search was not fruitful for her, it did not stop her from using other recipes she had found from other searches (such as from the veg box website and from Diabetes UK website). Her competency in cookery know-how enabled her to find recipes (information practice) and to adapt recipes (food practice). The cookery know-how seemed to be tacit and embodied. There was not an explanation in her diary as to what made the recipes 'normal' and the decision to adapt recipes seemed to be tacit using embodied cooking skills. Complete adapted recipes were presented in her diary. Below one of them is included. Theresa has added a note 'simple' implying the possession of cookery know-how linking information practice to food practice as if there was no trouble in being able to understand how to adapt recipes. Below is the complete recipe for leek and potato soup, which Theresa has written out in full and commented at the end 'simple'.

Figure 25 Theresa's diary: Cookery knowhow



In this way nutrition information practice and the skills used in information practice overlap with those in food practices such as cooking. The different practices are interlinked, each being dependent upon the other and identify the importance of cookery know-how in information and food practices and diabetes self-management per se.

Conclusion to Theresa's embodied information practice

The case of Theresa has emphasised the importance of the need for the diabetes to be embodied, to have accepted the diagnosis before T2DM information practice can begin. Once Theresa had accepted her diagnosis, she was able to start to take on information about diabetes and to learn how to live with it. Embodied diabetes creates an understanding, an opening up of opportunities for information practice. The process of embodying diabetes comes with it embodied tacit learning and knowledge which can be applied to further information practices. With the embodied diabetes comes the aspirations, the 'rules of thumb'. The preferences and beliefs influence the choice of specific types of information practice, in Theresa's case this seemed to be the interaction with peers, the friendships developed and the opportunity to share ideas with other people who have T2DM. In this way embodied diabetes enables information practice. Engaging in information practices add to

the skills and competencies available for use in further information practice and preferences influence the selection of information practice. However, skills and competencies are also needed to access the information for people with T2DM. Skills were needed in order to be able to make use of food labels to their full extent; without cookery know-how Theresa would not have been able to adapt her recipes to meet her 'rules of thumb'; the lack of follow up to the structured education session prevented the practice of sharing her experiences with others.

The varied meanings, the competencies used, and the materials needed underline the complexities in Theresa's nutrition information practices. The detailed analysis of Theresa's information practices has identified the importance of the embodied diabetes on how she undertook her information practice influencing each element of information practice: meanings, materials and competencies. Theresa's case will now be contrasted with Isobel who at the time of the study had diabetes for over 20 years.

6.2 Isobel: experienced nutrition information practices

Although Isobel was a similar age to Theresa also being in her 50s, she had had diabetes for over 20 years. Isobel lived at home with her family, husband, daughter and daughter's boyfriend. Isobel worked in a Government department at a managerial level. She often travelled to visit family. Isobel was a facilitator for a diabetes support group and said she took this role very seriously. She felt that she was knowledgeable about the condition and so considered it her responsibility to not only support the members of the group but to also pass on her knowledge about how to manage T2DM. Isobel's experience with her own diabetes meant that she had a well-developed 'rule of thumb' in how she managed her diabetes which she felt was at variance to the standard approach. This self-knowledge about what worked for her and her experience in managing T2DM are what make her a contrasting case to Theresa. While Theresa was newly diagnosed and trying to find information and to understand information to help her manage her T2DM, Isobel had formulated how she was going to manage her T2DM and wanted to use her experience to support others to manage their T2DM.

Context of Isobel's information practices

Isobel describes herself as principled and a 'researcher'. Her dispositions, her interest in food and eating, the enjoyment of the process of education coupled with life experiences shaped her approach to how she lived her life and managed her condition and influenced her T2DM information practice. Coupled with her embodied disposition of the need to search for and analyse information

and her need to ensure that she looked after her diabetes influenced her approach to selfmanagement.

Isobel's account began with her diagnosis of T2DM over 20 years ago, having been diagnosed with gestational diabetes ¹¹ during pregnancy. After the baby was born the gestational diabetes disappeared, however, following cessation of breast-feeding Isobel was subsequently diagnosed with T2DM. Like Theresa there was diabetes in the family including a close family member who did not take care of their diabetes in order to avoid complications and who did not appear to be concerned of the impact that their early death may have on their partner. When the relative died, Isobel felt 'very angry indeed with [them]', as she felt that they could have looked after their diabetes and prevented their widow from having to live on their own for so long. This incident influenced Isobel to work towards managing her diabetes, in the best way that she could. Isobel describes herself as having a 'policy' for the way she lives her life, with a focus on helping others with diabetes and the avoidance of medication. This led her to volunteer to become a support group facilitator. In the support group meetings Isobel's confident disposition means that she 'tends to drive the ideas and do quite a bit of the talking', often taking a lead in managing the group discussions and answering questions.

The meaning behind Isobel's information practice

Isobel's embodied and long-established dispositions are what drove her information practice once she had diabetes. She describes herself as 'not the kind of person that does things by half-measures' and a 'a researcher at heart'. Even before she was diagnosed with diabetes, Isobel describes her keen interest in food and eating. Isobel read about Frances Moore Lappé's 'Diet for a Small Planet' which focusses on the environmental impact of eating meat. Isobel explained that at this time she was young and idealistic and wanted to save the world; reading this book influenced her to become vegetarian. For Isobel, nutrition information practice was already embodied, was already part of her disposition and becoming vegetarian became part of her habitual practice.

In following the vegetarian diet Isobel explains how she was careful to balance different protein foods for their amino acid ratios to ensure her diet was healthy. Once Isobel was diagnosed with T2DM she was not only careful to balance the different types of proteins, but she explains that she

¹¹ Gestational diabetes is high blood sugar (glucose) that develops during pregnancy and usually disappears after giving birth (NHS (no date) Overview Gestational Diabetes London Crown Copyright accessed 6th April 2021 from https://www.nhs.uk/conditions/gestational-diabetes/)

also applied the current dietary guidelines for people with T2DM to her own diet which involved basing her meals around carbohydrate foods. However, as time went on Isobel found that she gained weight and needed medications to manage her diabetes and this led her to question her dietary approach. At this time Isobel's 'researcher' instinct came into play, she explains how she started to read about the potential positive impact of eating less carbohydrate on diabetes and weight management. Isobel tried the approach and found the process of eating less carbohydrate had a positive impact on her diabetes management, her weight and how she felt in herself. Following the low carbohydrate approach had not always been easy as Isobel found that her vegetarian diet was high in carbohydrate content and many of the foods eaten in her household and available to eat when away from home were high in carbohydrate. Isobel describes how she 'was fine for a while' but 'it started to slip' and so she returned to eating foods with a high carbohydrate content because it was 'easier' to eat what everyone else was eating around her. Her family said to her 'it's so much easier we don't have to make you anything else'. This led to her gaining weight. Finally, she resolved to avoid carbohydrate foods as much as possible so she 'went completely and utterly totally properly as low carb as [she] could'. In order to do this, she also decided to no longer follow a vegetarian diet. This change from avoiding meat to eating it came at personal cost, challenging friendships, as her 'best friend at the time almost stopped speaking to [her]' and affecting family mealtimes. However, Isobel felt this cost was worth paying, as the change in dietary habits resulted in weight loss, an increase in 'vitality' and an improvement in 'stamina'. The low carbohydrate (and high fat) meat eating approach is now an embodied part of her diabetes management and an influence on her nutrition information practice.

This discovery that following current diabetes guidelines for the dietary management of T2DM did not help her manage her diabetes coupled with early experiences had an impact on her beliefs. Isobel explains how her father was influenced by the book 'Pure White and Deadly' by John Yudkin which challenged established views about sugar, processed foods and carbohydrate intake. Also, how her reading 'Diet for a Small Planet' fed her youthful idealistic viewpoints. These experiences may suggest a mistrust in conventional viewpoints.

As with Theresa, Isobel's diary was filled with lists of foods that she had prepared for her family and eaten herself, emphasising her low carbohydrate approach to eating. Her diary entries illustrated her food practices, emphasising her skills in food preparation and embodied nutritional knowledge about foods that were part of the low carbohydrate/high fat diet she preferred to follow. She emphasised the specific foods she had selected with an explanation as to why she had chosen these

foods. This illustrated her extensive embodied knowledge about what foods constituted a low carbohydrate/high fat diet (her 'rule of thumb') and what she needed to do in order to be able to keep to the diet whilst also having enough to eat. This involved regular consumption of high fat foods such as cheese, cream¹² and nuts¹³. For example, she writes about eating a cheesy mushroom omelette, adding double cream to a vegetable gratin and talks about having 'at lunch time...30 grams or so of almonds...[or]some cold meat, I might have some cheese as well...'. Isobel chose the high fat snacks for lunch 'because they recommend it' on a low carbohydrate diet. She is consuming high fat foods to increase the satiety and to replace the energy from carbohydrate foods that she now avoids as part of her low carbohydrate diet.

Researcher instinct and desire to help people

Isobel's discovery that the low carbohydrate approach was beneficial to her and additionally that this was not the conventional approach led her to seek out researchers that wrote about following the low carbohydrate diet. Isobel explains that she started to search more widely and to make sure that she was not reading about one viewpoint as she felt that 'your view needs to be as rounded as possible'. This need to read widely was enhanced by Isobel being a support group facilitator at the time of the study. This role gave added meaning to her approach to information practice as she felt that she needed to 'be well educated' in order to be able to answer group members' questions but also to understand different viewpoints. Isobel wanted to be able to respond to questions not giving a 'black-and-white' answer but to be able to respond by exploring with the group members what foods they may find would help them. During the time of the study Isobel took part in an online diet and nutrition course. This she explains is part of her approach in trying to understand what the latest research is, not just so that she can help support the participants in the support group but also because she is aware that the conventional approach to diet is not low carbohydrate. Her aim she explains was to make sure that the dietary argument is not 'polarised', that is, that there are not arguments that one dietary approach for T2DM is better than another. Isobel had discovered that a lower carbohydrate dietary approach helped her to manage her T2DM, however at the time of the study the guidance was for people with T2DM to base their meals around carbohydrate. Isobel

¹

¹² For example, the NHS England (March 2019) 'Eat Well/Dairy and alternatives in your diet' states 'Most cheeses...contain between 20g and 40g of fat per 100g. Foods that contain more than 17.5g of fat per 100g are considered high in fat... Cream is also high in fat, so use this less often and in small amounts, too.' Crown Copyright [accessed 6th January 2021] available at https://www.nhs.uk/live-well/eat-well/milk-and-dairy-nutrition/

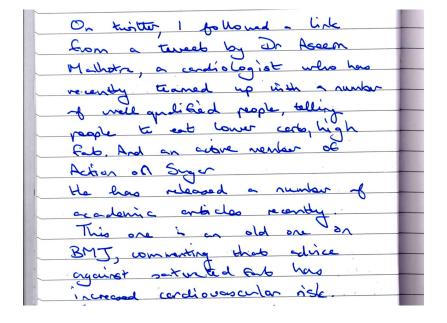
¹³ For example, the NHS England Eat Well (27 March 2019) states 'Nuts are high in fibre, and unsalted nuts make a good snack. But they do still contain high levels of fat, so eat them in moderation'. Crown Copyright [accessed 6th January 2021] available at https://www.nhs.uk/live-well/eat-well/

wanted to be clear in her role as support group facilitator that the standard guidance did not suit her T2DM and so inform the group that there are other approaches to managing T2DM.

Search engines, social media, broadcast media

Isobel's main source of nutrition information was from information obtained online. She signed up for Medscape¹⁴ but found the information impersonal and irrelevant. So, she now uses social media, particularly Twitter to find out about nutrition and T2DM. Using Twitter enables Isobel to find out about the person who is sharing the information, to find out their view, to be able to follow them to see what else they write about and to be able to directly access the tweeter's research. Isobel writes in her diary how she follows a researcher whom she respects. His work shows how he is trying to represent patients' experiences and views and he is not working in isolation but has 'teamed up with a number of well qualified people'. The use of Twitter to share the research allows Isobel to follow the link on the Tweet to the relevant article.





On twitter, I followed a link
from a tweet by Dr Aseem
Malhotra, a cardiologist who has
recently teamed up with a number
of well qualified people, telling
people to eat lower carb, high
fat. And an active member of
Action on Sugar.
He has released a number of
academic articles recently.

academic articles recently.
This one is an old one on
BMJ, commenting that advice
against saturated fat has
increased cardiovascular risk.

Isobel diary facsimile

Isobel diary transcription

¹⁴ Medscape defines itself as 'the leading online global destination for physicians and healthcare professionals worldwide, offering the latest medical news and expert perspectives; essential point-of-care drug and disease information; and relevant professional education and CME' Medscape (1994-2021) *Who we are*: WebMD LLC. New York accessed 6th April 2021 from https://www.medscape.com/public/about

Being able to follow a trusted person appears to have given an additional dimension to Isobel's information practice and she describes how checking her newsfeed at the end of the day has developed into a 'hobby'. The amount of information did not seem to deter Isobel as she describes herself as a quick reader and skilled at being able to decide whether to follow up on an information lead. Sources are checked to make sure the authors have a medical qualification. However, she does not 'dismiss people's blogs... and although they're limited... that doesn't mean you can't learn from them' as they are a source of useful experiences and different points of view.

Isobel enjoys the process of reading the research she finds. She also accessed other sources for information on the low carbohydrate diet for entertainment. These were usually television series such as television documentaries and diet series. They also helped to ensure Isobel has a 'rounded' view of the nutritional information available. While she does not always like the TV presenters, she finds that they 'signpost some good stuff' and found the inclusion in some documentaries on nutrition 'assumptions and ...audience manipulations... interesting'. Television programmes, particularly documentaries, were interesting to Isobel, not necessarily in what she learned or gained from them but in an understanding and appreciation of what others may gain from them.

The competencies of searching and criticality

Isobel's need to find out how to follow a low carbohydrate diet influenced her approach to her information practice. She used search skills to access a wide range of sources of nutrition information. Isobel's core information practice skills were being able to quickly read and interpret research articles and to apply criticality to the information she came across. She describes her approach of making sure that the source is written by a medical expert, or if not, she may still take an interest but be aware that the information may not be evidence based saying 'and if a thing looks a bit dodgy then [she] won't go there'. Not only were Isobel's searching skills well developed across a range of different platforms, but she was also able to identify when information was not trustworthy. Rather than read the information and be at risk of learning something that was not accurate, she would avoid the information and source altogether.

Isobel had sufficient knowledge to appreciate the challenges that those who are writing national guidelines on diet and diabetes face, and the difficulties in making sure that new emerging evidence is taken on board. Isobel was aware that not everyone felt that the low carbohydrate diet for T2DM was evidence based and had read how established sources of nutrition information had gradually taken on board that this approach may be effective. She said 'I've had conversations with people that

work at Diabetes UK who privately think that the low-carb thing is very sensible, but obviously as part of their job have to work within what the standard procedures are' and noted that in the new guidance from the British Dietetic Association on carbohydrate intake for people with T2DM 'there was a wee bit of movement but there wasn't an awful lot'. Isobel's concern was that while she felt that there was a lot of research confirming that a low carbohydrate diet was successful in managing T2DM, that many researchers were closed to the idea as this challenged their traditional viewpoints. She said that researchers are 'supposed to be open-minded'. Isobel's criticality skills and knowledge about diabetes enabled her to understand the complexity of developing nutritional guidelines for a population but at the same time her beliefs led her to mistrust the conventional established approach to the nutritional management of T2DM.

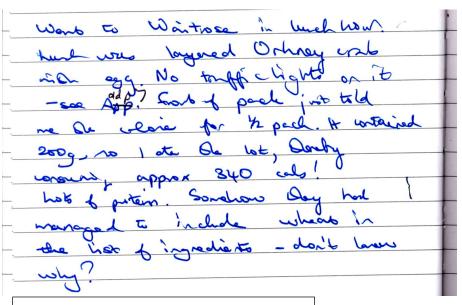
Food labels

Unlike Theresa who had found food labels, despite their limitations, to be useful in clarifying the 'hidden ingredients', food labels were not a source that Isobel found useful. Although many examples were included in her diary, these were included to illustrate their lack of value and to highlight the types of foods that Isobel ate as part of her 'rules of thumb'.

'Rules of thumb'

Isobel's 'rules of thumb' impacted on the way that she used the information on food labels. She used the section containing nutritional values to help her decide how much of a food item to eat, ignoring the guidance on the recommended portion size. The nutritional values per 100g were used to help Isobel decide how much to eat of a food item. For example, in the diary section and food label below of Orkney crab with egg, Isobel described her approach to making decisions as to how much of a food item to eat. She interrogated the nutritional values on the food label, identified the energy value per 100g, then the energy value for the full packet of food. She then compared the nutritional value of the full packet of food against her 'rule of thumb' as to how much she can eat and decided to eat the full packet.

Figure 27 Isobel's diary: Process used to analyse nutrition information on food labels



Went to Waitrose in lunch hour. Lunch was layered Orkney crab with egg. No traffic lights on it-see Add p7. Front of pack just told me the calorie for ½ pack. It contained 200g-so I ate the lot, thereby consuming approx. 340 cals! Lots of protein. Somehow, they had managed to include wheat in the list of ingredients-don't know why?

Top: Isobel diary facsimiles

Bottom: Isobel diary transcription

No traffic lights I presume it would be red?



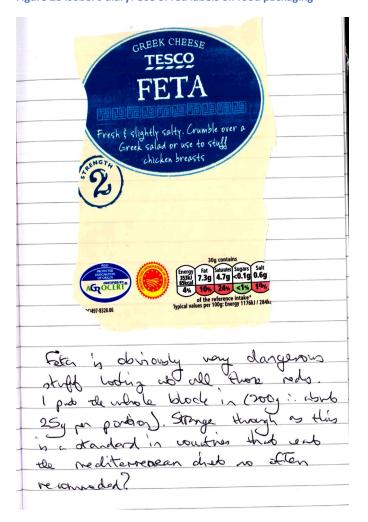
Using embodied knowledge when interpreting food labels

Isobel also possessed knowledge about nutrition and criticality skills which she demonstrated when talking about the value of the traffic light system to herself and to the general population. Isobel demonstrated skills in being able to interpret the traffic light system in use on food labels. She understood that foods labelled red for a component meant that the amount of that component in the food was not considered healthy for the general population. Her knowledge of her own 'rule of thumb' mean that she was also able to apply this information to her own diet and what she ate in order to manage her T2DM. Isobel explained that she said that she has 'generally ignored' the traffic light system as it was not relevant to her. Also, she was concerned that as the traffic light system aims to encourage limited consumption of foods labelled red, a moderate consumption of foods labelled amber and free consumption of foods labelled green, the system may inadvertently result in a reduced consumption of nutritious foods.

In the excerpt below from her diary she critiques the red label for fat on the feta cheese which she had included in a vegetable bake. Not only has she decided that the feta cheese is important in her low carbohydrate diet but she also wonders why it is labelled red and yet is a recommended component in the Mediterranean diet which people with T2DM were encouraged to follow at the time of the study¹⁵:

¹⁵ See Diabetes UK Nutritional guidelines 2011 19 http://www.diabetes.org.uk/About_us/What-we-say/Food-nutrition-lifestyle/Evidence-based-nutrition-guidelines-for-the-prevention-and-management-of-diabetes-May-2011/page

Figure 28 Isobel's diary: Use of red labels on food packaging



Feta is obviously very dangerous stuff looking at all those reds.

I put the whole block in (200g therefore about 25g per portion). Strange though as this is a standard in countries that eat the Mediterranean diet so often recommended?

Isobel diary facsimile

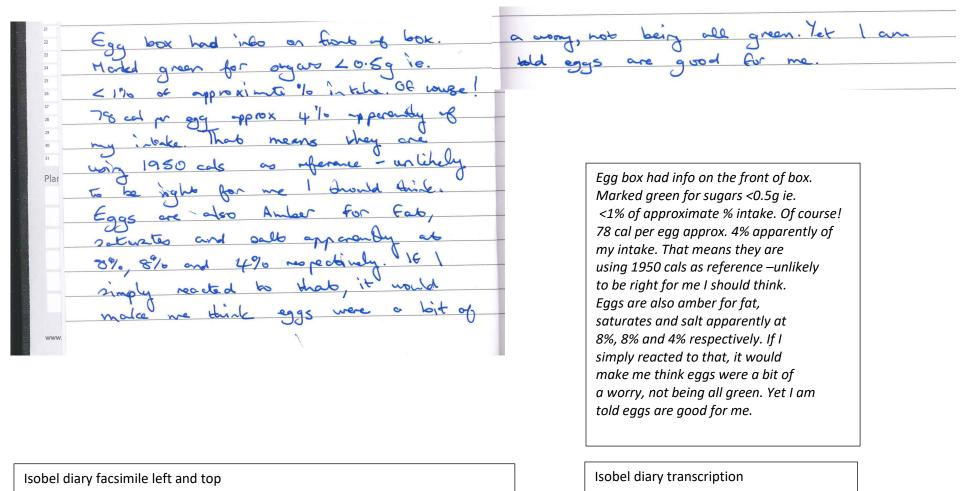
Isobel diary transcription

Although nutritional values were useful to Isobel to help her follow her low carbohydrate diet, the traffic light system where red is considered unhealthy and green is considered healthy was not helpful to Isobel. She explained that, as she was reducing her carbohydrate and sugar intake and replacing it with energy from fat, meant that food labelled red for fat in the traffic light system was likely to fit with her 'rule of thumb'. She had 'concluded that everything that was marked red was likely to be something that [she] was going to eat'.

Isobel had a further issue with the traffic light labelling system. Finding that the traffic light system on food labels do not consider different dietary approaches and are based on a standard assumption

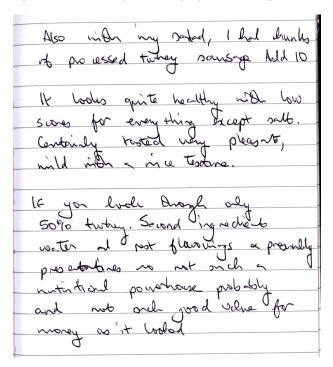
of nutritional requirements i.e. labelling high fat foods as red or amber when they may have healthy attributes meant they had little value to Isobel. The section below from Isobel's diary refers to the food label on a packet of eggs. Isobel notes the nutritional values and the traffic light categorisation of the fat content as being amber that is moderately high. This reinforced Isobel's view that food labels were of limited value to her. The categorisation was based on a standard energy requirement which she did not feel was appropriate for her as it was likely to be too high and the categorisation of the fat value as being amber may lead people to be concerned about the value as it suggests a moderately high i.e. a moderately unhealthy value. This may lead people to avoid eggs, when she had been told that they were a healthy food item:

Figure 29 Isobel's diary: Relevancy of nutritional information on food labels



Isobel also felt that the traffic light system may steer people away from foods that had added nutritional value towards foods with less nutritional value. Foods labelled red may, for example, have healthy attributes while foods labelled green may have unhealthy attributes and lack nutritional value. Isobel used two foods she had consumed to explain these ideas. Isobel had purchased some turkey sausage to have for her lunch but on the label, she noticed that although it was labelled green which would imply that the food was healthy, in fact the ingredients showed that the product was only 50% turkey. This meant that only 50% of the nutrients in the sausage were provided by turkey and she said 'it's this bit of turkey which has got 50% water in it and has been mushed up in a machine' and included the diary entry as follows:

Figure 30 Isobel's diary: Reviewing ingredients alongside nutrition information



Also with my salad, I had chunks of processed turkey sausage.

It looks quite healthy with low scores for everything except salt.
Certainly tasted very pleasant, mild with a nice texture.

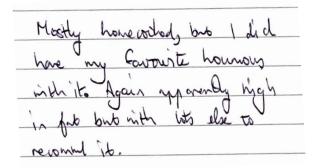
If you look though only
50% turkey. Second ingredient
water and rest flavourings & presumably
preservatives so not such a
nutritional powerhouse probably
and not such good value for
money as it looked.

Isobel diary facsimile

Isobel diary transcription

Isobel suggests that foods labelled green were more likely to be processed. While the label on these foods may imply that they are healthy to consumers, they may lack nutritional value and so she 'wouldn't touch [them] with a barge pole'. Similarly, Isobel believed that foods labelled red thus suggesting that they are unhealthy may in fact be healthy as there are other aspects to their nutrition apart from the fat content that made them healthy for her. She included the diary entry and food label as follows:

Figure 31 Isobel's diary: Critique of red labels

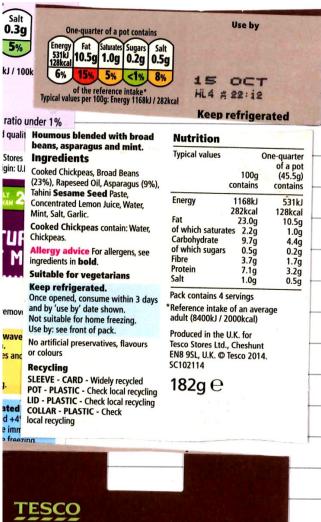


Mostly home cooked, but I did have my favourite houmous with it. Again apparently high in fat but with lots else to recommend it.



asparagus

houmous



Left:

Top: Isobel diary facsimile

Bottom: Isobel diary transcription

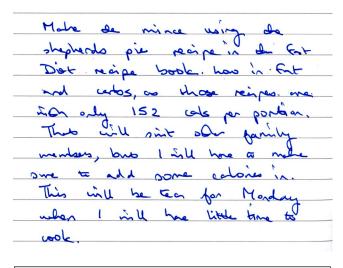
Right:

Isobel diary facsimile of broad bean asparagus and mint houmous food label Although green labels on processed foods may be considered healthy, they may not contain the nutrients that are inherently in the product from which they have been made and red labelled products may have ingredients and nutrients in them which would help to manage T2DM. In this way Isobel was concerned that the traffic light system, which aims to encourage consumption of foods labelled green and discourage consumption of foods labelled red, may inadvertently result in the consumption of more unhealthy foods and less healthy foods.

Recipes and cookery know-how

Isobel used her cookery know-how and embodied knowledge about food and nutrition to be able to source and adapt appropriate recipes that met her 'rules of thumb'. Isobel accessed low carbohydrate recipes to help her follow her low carbohydrate diet. For example, she made a low carbohydrate bread from a recipe from a researcher and author on low carbohydrate diets. However, she often adapted recipes to ensure they met her rule of thumb. In the example below Isobel has found a low carbohydrate recipe but notes that she will need to make sure that she consumes some additional calories to make up for the lower energy value of the final dish as it is low in energy as well as carbohydrate ¹⁶.

Figure 32 Isobel diary: Cookery knowhow



Made the mince using the shepherds pie recipe in the Fat Diet recipe book. Low in fat and carbs as those recipes are just only 152 cals per portion. That will suit other family members, but I will have to make sure to add some calories in. This will be tea for Monday when I will have little time to cook.

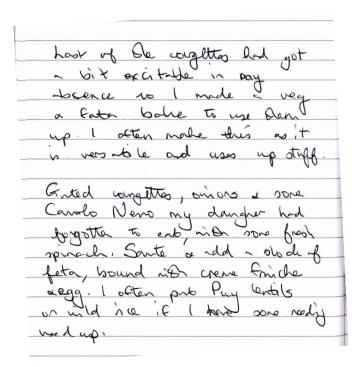
Isobel diary facsimile

Isobel diary transcription

¹⁶ For details on what constitute starchy foods see NHS (March 2019) Eat Well-Starchy foods in your diet accessed 6th January 2021 from https://www.nhs.uk/live-well/eat-well/

Her recipes are also notable for their low carbohydrate content and the addition of high fat ingredients for satiety. In this recipe below Isobel is describing how she adapts a tried and tested recipe using courgettes adding in other ingredients as available. Isobel adds feta cheese and crème fraiche to the courgette bake.

Figure 33 Isobel diary: Recipe adaptation



Last of the courgettes had got a bit excitable in my absence so I made a veg & feta bake to use them up. I often make this as it is versatile and uses up stuff.

Grated courgettes, onions and some cavolo nero my daughter had forgotten to eat, with some fresh spinach. Sauté & add in a block of feta, bound with crème fraiche & egg. I often put Puy lentils or wild rice if I have some needing used up.

Isobel diary facsimile

Isobel diary transcription

In this way Isobel has used both her cookery know-how and her embodied knowledge to adapt recipes ensure what she eats meets her 'rules of thumb' about eating less carbohydrate in order to manager her T2DM.

Conclusion to Isobel's embodied information practice

Isobel's embodied disposition potentially developed from childhood experiences influenced her nutrition information practices. Isobel had shown an interest in food and eating as a teenager and followed a vegetarian diet. But finding that she had T2DM and the conventional high fibre low fat approach did not help her manage her diabetes, she discovered that the newly emerging low carbohydrate approach did help. Her information practice was influenced by a desire to know more about the approach as much for herself as for the support group that she helped facilitate. Isobel used low carbohydrate recipes, looked at energy value on food labels, read about the low carbohydrate approach from trusted researchers and used their resources. Isobel critically evaluated

the information she came across. The information found on food labels was judged for its standard nature, not taking into account different dietary approaches which may be healthy. Information accessed online was carefully reviewed in order to ensure that evidence-based information was read, however information that was about life experiences was not discounted as this was considered to provide useful information about how to live with T2DM. Isobel's searching, interpreting and criticality skills and knowledge about nutrition facilitated her information practice and her experiences with different sources of information were drivers to her information practice.

6.3 **Summary**

These two participants were selected for the differences in their stages of embodying their T2DM. Both had embodied their diabetes and so were able to undertake nutrition information practice, but the stages of their embodiment meant their information practices were different. While Theresa was learning about diet and diabetes, Isobel was researching new ways that could assist her and others in the management of T2DM. Theresa was still learning about how to manage her T2DM and was trying to reduce her fat intake. Isobel had just changed her dietary approach to a low carbohydrate approach which involved eating more fat in her diet. She was still learning about and researching the value of this approach to people with T2DM. Although Theresa had benefitted from attending a structured education session, she had found this limiting as there was only one session and was now attending a support group for people with T2DM. Isobel was the facilitator for a diabetes support group. Both believed in those approaches in assisting them and others in managing T2DM. Both included food labels and recipes in the diaries. Both did not find food labels of great value. Theresa found them confusing. While Isobel found the nutritional values on the side of the pack were useful the traffic light system was not relevant or helpful. While Theresa did search online for recipes and information from Diabetes UK, Isobel's use of technology was more extensive. Both adapted recipes according to their preferences and needs. Theresa adapted recipes so that they were lower in fat, while Isobel adapted recipes so that they were higher in carbohydrate and lower in fat.

Theresa and Isobel were used to illustrate the link between embodied diabetes and diabetes nutrition information practice. The embodied diabetes, that is the acceptance and coming to terms with diabetes was particularly apparent in the case of Theresa who was not able to undertake any information practice until she had come to terms with her diabetes. This contrasted with Isobel whose embodied diabetes enabled her to explore and research new approaches to self-management for herself and others. By using participants at different stages of their embodiment who were

following different dietary approaches has assisted in highlighting how embodied diabetes shapes information practices.

The breaking down of practices into the elements of meanings, materials and competencies has uncovered the influences and the way that these two participants undertook nutrition information practices. The meanings and competencies illustrate why particular information practices were different for each participant. While both women were primarily interested in managing their T2DM, Theresa's focus was on how to live with T2DM while Isobel was on how to help others live with T2DM as her own diabetes was now under control. Both struggled with the value of food labels in helping them to manage their T2DM. While Theresa could identify whether a food was high in sugar she was not able to decipher the more complex information on a food label and use it to make decisions. Isobel was able to understand food labels but did not find them useful as the information did not relate to her 'rules of thumb' about eating. While Isobel found the nutritional values on the side of the pack were useful the traffic light system was not relevant or helpful. Foods labelled red may have healthy attributes and foods labelled green may have little inherent nutritional value. Both recorded the foods they prepared and what they ate in their diaries. This aspect underlines how information practice leads to embodied knowledge and the interconnectedness between practices such as nutrition information practices and food practices. The social aspects of some forms of information practice appeared to be of value to both Theresa and Isobel. Theresa greatly valued the interaction with peers and Isobel valued the interaction with the members in the group where she is a facilitator. However, Theresa's information practice did not go further into searching for information online beyond looking for recipes and accessing the Diabetes UK website. This is where their information practices diverged. Isobel's disposition of being a 'researcher at heart' and a need to ensure she gave a balanced viewpoint to her group members encouraged her to actively search for information online and through social media.

Using the two contrasting cases, one who was early on in their embodied diabetes and one who was experienced in their diabetes management underlines the importance of information practice to people with type 2 diabetes at whatever stage of diagnosis and embodiment. Early in the diagnosis the practice was about survival, finding out what would be healthy to eat. Later in the diagnosis the practice may move to learning the context of diet and self-management in order to review their dietary approaches to improve their diabetes management. Although several other participants did undertake extensive reading about diet and diabetes, Isobel was unusual among the participants in her use of social media (Twitter) and accessing research articles. Although she was selected as her

experience appeared to be in such contrast to Theresa, in fact her case bore similarities to Theresa as both carried extensive cookery know-how which they applied to adapting the recipes they used and the way they prepared their foods.

The chapter has highlighted the great variation in sources of information available to participants about nutrition and diabetes. Broadcast media, that is newspapers and television, the internet, recipes, food labels, books, social media, clinical websites, research journals, education groups, dietitians, nurses, GPs, other people with diabetes and the body were all referred to by Theresa and Isobel. The wider group of participants also utilised a wide range of sources, however food labels and interactions with peers were sources that were accessed by all participants.

The limitation of the nutrition information on food packaging in assisting people with T2DM to self-manage is emphasised. Theresa's experiences were similar to the group as a whole in finding them challenging to use. However, by exploring her case in more detail the structured education session was identified as the source of explanation of how to use food labels and so underlines the impact that one information practice can have on another and the interconnectedness between practices. While the traffic light system was not of value to Isobel the nutritional values served a purpose in identifying appropriate foods. Other participants also used the nutritional value section to identify appropriate foods.

This chapter has also highlighted the value in peers as being a source of information in assisting people to manage their T2DM. Theresa referred specifically to the impact that structured education had on her being able to manage her T2DM. While the limited access to structured education per se was identified in the last chapter, Theresa's experience has also shown the limitations in her experience of the format of structured education in that it was delivered in a single session. The importance of the social interaction when engaging with peers as a source of information is highlighted. Using Isobel as a case has identified the potential impact that facilitators of peer support groups may have on their group.

These two chapters have identified the range of nutrition information that people with T2DM access and use and the impact of embodied diabetes and skills and competencies on their experiences. Food labels although readily available appear to have limited value, while engagement with peers has possibilities in helping people with T2DM with learn to live with their diabetes. In the next chapter I discuss the significance of these findings alongside the research literature in this area.

7 Chapter Seven: Discussion and conclusion

7.1 Introduction

This study set out to explore the nutrition information practices of people with T2DM and found that nutrition information practice is tacit and hidden, is situated within and entangled with food practices and is influenced by the embodiment of T2DM. This chapter begins with an overview of the findings of the two components of the study. These are linked to the literature on nutrition information practices with a focus on the key themes of food labels and peers. Food practices relating to food provisioning and their interconnectedness with nutrition information practices are reviewed and information behaviour models are critiqued. These are followed by an identification of the theoretical contribution that the study makes, recommendations for practice and further research, and finally the strengths and limitations of the study. The chapter finishes with the conclusion.

In order to meet the aim of the study a systematic review using a narrative approach and an empirical research study using the diary-interview approach was undertaken. The systematic review identified that nutrition information is fundamental to being able to self-manage T2DM and that the complex nature of nutrition information may be a limiting factor in people with T2DM being able to effectively make use of it. However, no study included in the review explored nutrition information practice from the point of view of people with T2DM and there were no studies that considered the tacit and embodied nature of food and information practices. The diary-information methodology was developed in order to enable an investigation of these issues. The unstructured diary enabled participants to record the nutrition information that they came across and, along with the interviews, enabled identification of the entangled nature of information and food practices.

Chapter 4 presented the context for the nutrition information practices undertaken by the participants. Food practices were tacit and mundane, but nutrition information practice was key in enabling participants to be able to identify their 'rule of thumb' and to adapt their practices to ensure that their T2DM was well managed. Chapter 5 investigated the information practices involving food labels and peers as sources of nutrition information referred to and or used by all participants. The source of nutrition information was found to impact on the information practices and different sources were found to have different meanings for participants and to utilise different competencies. Chapter 6 explored the nutrition information practices of two participants who were

at different stages of living with T2DM. The stage of the embodied diabetes was found to influence information practices. The meanings behind information practices were found to influence why nutrition information was undertaken, while the skills and competencies were found to impact on the materials used and their effectiveness in helping the participants.

7.2 Coming to terms with diabetes and its influence on information practice

This study identified the impact that the embodiment of diabetes has on information practice. Embodiment encompasses mind and body, where the mind and body meet or are intertwined with each other. Both experiences (mind) and physical aspects (body) of life become part of an individual's identity and inform the way people think about themselves. (Crossley, 1995; Merleau-Ponty, 1962, pp. 324, 379; Williams & Bendelow, 1998, ch 3).-While people who are newly diagnosed with T2DM may be aware that they have diabetes i.e. they are aware of its physiological presence, for them to be able to undertake T2DM information practices they need to have come to terms with the diabetes diagnosis and accept it so that it becomes part of the way that they perceive themselves. In this way the process of embodiment of T2DM involves both the mind and the body. The embodiment of diabetes, taking ownership of diabetes and practices relating to diabetes becoming habitual and tacit was key to being able to undertake information practice. For example, Theresa was not able to effectively undertake information practice until she had accepted her diabetes. Once she had, she instinctively undertook information practices, accessing information sources such as the peer support group and using food labels to inform her food choices. Similarly Funa (2012) and Whittemore et al. (2002) in their studies involving participants with T2DM found that acceptance and integration of the diabetes was needed before self-care could be undertaken-

What impacted on Theresa's ability to come to terms with diabetes was her life experiences, which led to fear of having diabetes. Isobel's embodied diabetes was impacted by her life experiences but instead of this leading to fear, led to her proactively finding out about diabetes and how best to manage her condition. Individual experiences and the way that they perceive these experiences impact on the process of embodiment and being able to undertake information practice (Engman, 2019; St. Jean, 2012). Those who develop a fear of having diabetes and a fear of ill-health in general, may prefer to not interact with information about their condition. While those whose early experiences are coupled with a disposition that enjoys information may find interaction with nutrition information a natural and automatic process.

While Theresa had sufficiently embodied her diabetes at the point of noticing the advert for the peer support group session at her local supermarket, the idea of being able to learn alongside others was clearly important to her. Indeed, it was the ongoing nature of the support group that was empowering for her and conversely the one-off structured education session that she found so disappointing. She wanted to be able to find out how the other members in the structured education session had got on, she wanted to know their practical experiences. Lawton and Rankin (2010) explored the concept of sharing and learning alongside others with people with T1DM attending a group education programme. Participants initially felt vulnerable in talking about their diabetes management in front of other group members but once there they were able to share their worries, and through discussions with others and hearing lay experiences, were able to reach an understanding about how to manage their diabetes. Michael (1996) who interviewed 17 people with long term conditions including diabetes, found that the type of learning needed to help with the integration (or embodying) of the disease involved a process of trial and error especially alongside others with similar conditions. This was as opposed to a formal education programme covering the latest developments. This suggests that there is a need for ongoing support for people with T2DM that facilitates sharing of experiences and continued learning and embodiment of the disease.

7.3 Information practice elements

This section draws on the elements of practice theory to explain the information practices of people with T2DM. Meanings were what drove information practices. The systematic review and the empirical research study identified the need for people with T2DM to be able to learn to live with the condition alongside their daily lives. For example, Meyfroidt et al. (2013) found that their participants wanted information about diet in order to self-manage, and Fitzgerald et al. (2008) found that their participants wanted to be able to apply information in order to make healthy choices. In this study the meaning behind the information practice depended on the source. For example, participants wanted to find out specific information from food labels that enabled them to meet their rules of thumb while the meaning behind the information practice involving peers was about picking up 'things from other people' (Helen). Although the need for specific information was identified in the systematic review; for example, both Ball et al. (2016) and Scott (1997) found that their participants wanted individualised advice that took into account the foods that they ate, this need for individual advice had less emphasis in the empirical research study. Instead, the participants wanted information so that they could apply it to their own lives, so that they could make their own decisions about what to eat.

The empirical research study found that beliefs about food influenced information practices. For example, Susan's belief that sugar in any form including that which was not a free sugar (NHS, 2020) was unhealthy, influenced her to explore the total amount of sugar in the foods she ate. This included food such as milk and crackers which are not normally considered foods that people with T2DM should be wary of due to their sugar content (Diabetes UK, No Date-b). Susan applied the total sugar information she read on the food label and selected the version with the lower amount. Similarly Cohn (1997) found in his study at a diabetes day centre with people with diabetes, that decisions about what to eat were made based on participants' own beliefs and judgements about what would be good for them.

The empirical research study identified the need for competencies and skills in order to be able to undertake information practices. Participants relied on embodied lay nutritional knowledge and cookery know-how in order to be able to make use of the nutrition information that they accessed. For example, Theresa using her cookery know-how identified that the recipes aimed at people with T2DM were similar to her own recipes, which she was subsequently able to adapt. The systematic review also identified the importance of cookery know-how in managing T2DM. For example, Lawrence et al. (2017) found that their participants wanted information on cooking in order to be able to prepare healthy foods and Byrne et al. (2017) found that the group education programme that included cooking skills had a positive impact on patient outcomes.

In order to be able to make use of food labels, participants in the empirical research study found they needed specific skills. For example, their lay knowledge about the colour coding system on the front of food packaging enabled participants to apply this to their food choices. However, their lack of lay nutritional knowledge prevented them from being able to interpret the information about total sugars on the back of food packaging. Participants felt that food labels were overwhelming, and Lisa explained that having numeracy skills enabled her to understand the figures on the food labels and to use them. She therefore surmised that if people did not have these skills, they would not be able to use food labels in their decision making. While finding food labels overwhelming and the lack of numeracy skills in being able to use food labels was considered a potential barrier to being able to make effective use of them, this barrier was not an overt finding in the literature review. Studies included in the systematic review did find that participants had difficulty in interpreting the information such as the difference between sugar and carbohydrate (Kessler & Wunderlich, 1999) and needed more guidance on how to apply the information on food labels (Lawrence et al., 2017), however, few linked the challenges with food labels to the need for specific skills and competencies.

Participants in the empirical research study felt that presence of communication and collaboration skills and the willingness to share and exchange of ideas were core competencies needed in order to be able to undertake information practice particularly that related to peers. The systematic review identified some research in this area. Mphwanthe et al. (2021) found that their urban participants in Malawi had access to a peer support group led by a retired nurse which enabled the sharing of information between attendees. Although the other studies included in the systematic review exploring information practice involving groups, that is Byrne et al. (2017), Martins et al. (2014), Waller and Tzeng (2011), Watson and DuFourd (1992) and Murrock et al. (2013) did not identify the use of communication and collaboration skills and the willingness to share and exchange ideas. However recent research exploring information behaviour in people with T2DM, undertaken by Broekhuis et al. (2020) did identify that information is often shared between people with T2DM.

The exploration of Theresa and Isobel's information practices exposed the wide range of materials that they both accessed and engaged with. This use of a wide range of materials by people with T2DM in information activities has also been found by Longo et al. (2010), Kalantzi et al. (2015), Broekhuis et al. (2020); Meyfroidt et al. (2013) and Kuske et al. (2017). However, this current study has sought to expose that information practice for people with T2DM is equally impacted by the meanings that drove the information practices as well as the skills used in order to be able to make use of these information practices. The findings demonstrated that all participants accessed and made use of food labels and peers and these two sources will now be discussed in turn, starting with food labels

7.4 The value of food labels to people T2DM

The empirical research study and the systematic review identified that being able to use food labels was challenging for people with T2DM. Although some participants explained that they would avoid purchasing or consume smaller portions of foods labelled red within the traffic light system. However, finding the information on food labels overwhelming, not being able to understand the figures on the food labels and difficulties in appreciating the differences between different types of carbohydrates were shown to be particularly challenging. Participants were able to use the colour coding system to make choices but found it difficult to interpret the figures on the front of the pack. However, Isobel found the colour coding system not applicable to her 'rule of thumb' for managing T2DM. Croker, Packer, Russell, Stansfield, and Viner (2020) suggest from their systematic review on the impact of food labels on consumption and purchase, that front of pack food labelling encourages

healthier food purchasing. However the narrative review on the impact of food labels on the identification of healthy foods and consequent shopping choices undertaken by Temple (2020) suggests a more nuanced response that there is just a 'small degree' of success in food labels encouraging the purchase of healthier foods. Neither study incorporated studies relating to type 2 diabetes in their review.

Food labels are proposed as a key public health intervention developed in order to assist with the prevention and the management of long-term conditions such as T2DM. However, the systematic review and the empirical research study suggest that people with T2DM may not be able to make the most of the information that food labels provide or use these to manage their condition (Fitzgerald et al., 2008; Gray et al., 2014; Kessler & Wunderlich, 1999; Lawrence et al., 2017; Miller et al., 1997). Although the studies from the systematic review did not specifically identify issues with interpreting the figures on food labels, this has been found by other research. For example Rothman et al. (2006) found in their study with 200 patients recruited from GP practices (41% with a long term condition including diabetes) that participants demonstrated difficulties in understanding food labels. While the presence of low-level numeracy and literacy skills was linked to difficulties in interpretation, even those with high levels of literacy and numeracy found food labels difficult to understand. This underlines the challenges for people with T2DM in being able to interpret food labels and concurs with the empirical research study.

7.5 Peer support groups: sharing as an information practice

The key value of the information practice involving peers was the ability to be able to collaborate and share ideas about food, eating and cooking. Participants in the empirical research study explained that what to eat was the 'top subject' for discussion (Gary) at peer support group sessions; Oscar spoke about 'picking up suggestions' on how to live with T2DM and Ruth spoke of recipes to increase vegetable consumption. However, it was not just recipe ideas or tips on how to live with T2DM that were shared, it was also emerging new ideas of what sort of foods to eat that were shared. For example, Isobel talked about how she shared ideas gleaned from her information practices such as the emerging idea of low carbohydrate diets as an alternative to her perception that the current dietary emphasis is on a high carbohydrate intake. In this way peer support groups were vehicles for sharing new ideas on how to live with T2DM.

The role of peer support groups as 'information brokers' in the provision of 'how to live with' information was identified by Johnson and Case (2012, p. 177). However, the supportive nature of

peer support groups for people with T2DM along with their potential to have a positive impact on clinical outcomes has also been identified (Arney et al., 2020; Aziz et al., 2018; Funnell, 2009; Simmons et al., 2015). Although the systematic review found that group education sessions increased knowledge and practical skills, only Mphwanthe et al. (2021) identified peer support groups as a source of nutritional information. However other studies that were not identified in the systematic review have found peer support groups as sources of information. For example Arney et al. (2020) in their study with veterans with T2DM found that practical skills on preparing healthy meals were valuable outcomes from the peer support group sessions and Veinot (2010), in their study with 34 people with HIV/AIDS, found that practical information shared between peers was valued by the participants. Broekhuis et al. (2020) also found that sharing of information was an important aspect to information activities and propose that developing a social network for people with T2DM may help to support ongoing self-management behaviours. Additionally Lloyd (2010) proposes that the acquisition of embodied practical knowledge, is achieved through sharing of information within a community. The value of sharing practical experiences in group settings with people with diabetes was also identified by Lawton and Rankin (2010) with those with type 1 diabetes and Michael (1996) with those with T2DM. While support groups have been identified as being valuable to people with long term conditions there appears to be less research relating specifically to their potential value in the provision of nutrition information to people with T2DM.

The non-specific nature of the information shared in peer support groups in the empirical research study (e.g. 'picking up suggestions' (Oscar) on how to live with T2DM) and the sharing of experiential information may be an indication as to the reason why people with T2DM may not wish to attend structured education. Information practice is embodied and instinctive. Food practices are complex and tacit activities and as such people with T2DM may not be aware of how education could guide them to making decisions about what to eat especially if they have already developed their own 'rules of thumb' about what foods are healthy for them. Rather than couching group sessions or indeed any information about T2DM in terms of education, the sessions may be better marketed as providing information and or helping people to live with T2DM. In this way there may be reassurance that 'rules of thumb' and embodied knowledge are recognised, the information given will be sympathetic to the participants and the sessions will meet people where they are in the way they manage their T2DM. The name 'structured education' implies something specific that will be taught, when what people with T2DM appear to find most valuable from the group sessions is simply being with others like themselves, finding out how they got on and 'picking up suggestions'. Indeed Horigan et al. (2017), in their systematic review exploring why patients choose not to attend

structured education programmes, found that one of the reasons why people with T2DM do not attend structured education was that they could not see how the session would be of benefit to them.

Although many participants had not received referrals to group education, this current study has identified the value in attending sessions with peers in that through information sharing and collaboration they were a source of experiential information on how to live with T2DM. While participants were positive about their experiences as many were regular attenders at peer support sessions, this was to be expected, yet participants did suggest that group meetings may not be for everyone and that this may be related to the way that groups were run. The challenges of managing peer support programmes to ensure that groups are facilitated in a 'democratic manner' providing neither 'paraprofessional' advice nor acting as 'illness companions' (Simmons, Bunn, Cohn, & Graffy, 2013) has been identified along with the importance of avoiding a situation of 'learned helplessness (Lawton & Rankin, 2010, p. 492). Indeed, a large study investigating the impact of peer support sessions found that the skills and personality types of facilitators were important in ensuring an environment of equality and the success of the group (Holman, Simmons, Ockenden, & Graffy, 2019). The way that the group was run in ensuring that participants in the empirical research study were able to have their questions answered was identified as being important by two of the group facilitators recruited into the study, Isobel and William. However, Isobel also spoke about the importance of not giving her own viewpoint as to how best to manage T2DM despite finding that following the dietary guidelines prominent at the time of the study did not help her to manage her T2DM. There appears to be limited research exploring how voluntary group facilitators manage their own views and experiences in looking after their T2DM.

The empirical research study found that the participants appreciated the supportive environment and the availability of practical information in the support groups. However, the impact of the personality of support group facilitators in providing information and this influence on the participant information and food practices has been identified. Also Funnell (2009), Simmons et al. (2013) and Dennis (2003) note the importance of the provision of accurate information in peer support groups. Peer support groups have the potential to share new information that may not yet be in the public domain or overtly incorporated into guidelines. Indeed, by sharing experiences with different dietary approaches from the point of view of patients through their lived experiences as opposed to in a controlled environment (such as clinical setting or research project), new concepts in the dietary management of T2DM may be revealed. However, whilst no evidence of harmful

information sharing was found in this study, with the increased availability of non-evidence based information via the media (Cooper et al., 2012), internet (Weymann et al., 2015) and social media (Wang, McKee, Torbica, & Stuckler, 2019) there may be a potential for the sharing of inaccurate information and for this to be detrimental (Johnson & Case, 2012, pp. 18-21).

In this section the elements that comprised the information practices of the participants have been discussed. Through using this approach the limiting nature of food labels to helping people to manage their T2DM and the core competency of sharing information used by participants when undertaking information practice involving support groups has been exposed. The next section discusses the links between nutrition information practice and food practices.

7.6 Interconnectedness of information practices with food related practices

In the empirical research study food practices were found to be interconnected and at times entangled with information practices. Rather than food practices and information practices being discreet and separate, practices were entangled with each other (Wills et al., 2013). For example, Theresa applied her newfound knowledge about what to eat to her recipe adaptations and her decisions about what to cook; Penelope's embodied knowledge about the nutritional value of foods impacted on the type of food she purchased as well as the foods she chose to cook; Ruth cited checking food labels alongside reducing portion sizes and eating more fish. In this way food practices influenced nutrition information practices and vice versa; and food practices were part of nutrition information practices and nutrition information practices were part of food practices and information practices involving one material overlapped with other information practices. This link between practices was also identified by Wills et al. (2013) who found that kitchen practices involved a range of practices not just those involving food and that these different practices were 'intertwined' (ibid, p. 40).

In order to conceptualise the connections between practices, Shove et al. (2012) describe these as complexes of practices where each practice is dependent upon another and bundles of practices which are loose-knit connected by their co-location (ibid, p. 87). Castelo et al. (2020) showed how food practices could be a 'complex' (noun) or a network, linked to other practices through a 'nexus'. That is a network with each practice interconnected with another. St. Jean (2012, p. 261) in her study exploring the information behaviour of people with T2DM found that information activities were interconnected with other self-care activities. However, both studies suggest that practices are overt and separated. Hennell et al. (2020) identified alcohol consumption amongst young people as

a bundle of practices with each separate practice being dependent upon each other in order to occur. Similar interconnections were seen in the empirical research study. For example, Danielle checking her recipes while making the shopping list and Oscar noticing the traffic light system panel on food labels while shopping. Information practices were also applied to learning new skills and how to live with T2DM; for example, Frances learned about the impact of the food she ate on her blood sugar levels and Ruth linked her blood test results with the changes she had made to what she ate. However, there was not always a defined relationship between information practices and other practices. Instead, embodied knowledge (competence) ensued from information practices, the origin being unclear, which then influenced diabetes food practices. For example, Victoria's indication that she had skimmed milk because it met her 'rule of thumb' and William's wife using a fat spray in order to prepare oven baked chips which contained less fat.

The source of the information and the timing and enactment of the information practice was often unclear; however, the practice had resulted in embodied knowledge which participants applied to their food practices and their self-management and these practices themselves were tacit and embodied. In this way information practices from the past lead to current embodied knowledge which inform future information and food practices. Wills et al. (2013) identified the 'entangled' nature of information and other food related practices, the use of embodied knowledge to inform decision making and the lack of clarity as to the source of the information (see for example p. 36) in food hygiene practices. The empirical research study suggests that this entanglement also operates in relation to food related practices and nutrition information practices.

7.7 Information practice versus information behaviour

This study has found that the process of information practice is tacit and embodied. The study draws on the elements of practices (meanings, competencies and materials) (Shove et al., 2012) to explain the process of information practice. However, a key finding was the embodied nature of information practice and its links to other practices, in this case the link between nutrition information practice and food practices, were tacit and hidden. Food practices relied on embodied knowledge that had been developed from nutrition information practices.

There is limited research which has explored information practices, especially with people with T2DM. Savolainen (2008) drew on the concept of practice theory in his study with environmental activists and unemployed people. He found that information practices depended upon embodied knowledge and were habitual (ibid, pp. 202-203). An example of a taken for granted (or embodied)

information practice that is given is the everyday process of checking the news utilising different sources (newspaper, radio, television, internet, mobile phone). The key aspect of information practices is that they relate to everyday behaviours and as such the idea of an information need associated with them is likely to be hidden. Access to information is a key part of being able to self-manage long term conditions (Johnson & Case, 2012, p. 15). While there is less research exploring information activities (a term used to incorporate information behaviour and information practice) in people with T2DM than other long term conditions such as those with cancer, there is some research that has explored information behaviour (Broekhuis et al., 2020; Kuske et al., 2017; Longo et al., 2010) and nutrition information behaviour of people with T2DM (Meyfroidt et al., 2013).

Information behaviour includes the process of how people access and use information incorporating the components, information needs, information seeking and information use and the active and passive acquisition of information. The inclusion of the concept of active as well as passive information seeking (that is not being aware that an activity is being undertaken and not having any obvious intention of using information accessed passively) implies that there is an overt purpose to information activities. However research suggests that information activities are instinctive (Spink, 2010), and as this current study has exposed are embodied and interconnected with other activities. The model developed by Longo et al. (2010) identified the context and personal influences on information behaviour, the links with other self-care activities, and emphasises the overt nature of health information behaviour. However, the model does not include personal attributes such as beliefs and embodied knowledge and the embodied interconnectedness with other patient activities.

Broekhuis et al. (2020) utilised Longo et al. (2010) as a theoretical framework in their study of information activities in the daily lives of people with T2DM. Similar to the empirical research study they found that food activities were triggers for information activities and that health information activities were 'intertwined' with everyday life. For example, cooking a meal triggered the checking of nutritional information online and influenced the food provisioning process. The study was also able to identify that people with T2DM are not always able to find nutrition information. However, this current study with its focus on nutrition information practices was able to identify the holistic reasons for information practices, the competencies needed in order to be able to undertake information practices and the overlap between other practices. By identifying that information practices are influenced by dispositions and beliefs as well as by aspirations to self-manage and require numeracy skills, cookery know-how and embodied knowledge in order to be enacted, shifts

the focus away from the argument of active and passive and away from seeing information activities as overt and discrete. Similarly McKenzie (2003) used the diary/diary-interview approach (where the researcher made the diary entries following telephone contact) with 19 Canadian women pregnant with twins, to explore their everyday information seeking. They propose that the information behaviour theory does not take into account all the activities that may be related to information such as connecting and interacting with information and all the different modalities by which information could be accessed.

The concept of sense-making as identified by Dervin (1998) and utilised by St. Jean (2012) in her study on the information behaviour of people with T2DM, is about people making sense of the world by crossing knowledge 'gaps' though information activities. Although St. Jean (2012) identified that people with T2DM may not be aware of their information needs which she terms as incognizance, there was an emphasis on the need for information. However, this current study identified that information practice was more than finding out information. It was an embodied process that took place alongside the skills and competencies that the participants possessed and the materials that they came across. Separating meaning such as gaps in knowledge as proposed by Dervin (1998) suggest that information activities are simple and one way. Instead, the empirical research study found that information practice is subtle and nuanced and is impacted equally by the three elements of meaning, materials and competencies.

Cox (2012) in his expert opinion paper and McKenzie (2003) in her study both suggest that one of the issues with the idea of information behaviour is that it has its basis within psychology and the individual need for information as opposed to seeing information as part of practices. The example of Savolainen (2008) and his *Everyday Life in Information Seeking* model is given as challenging the individual need for information to seeing information as part of social practice. However Cox (2012) critiques this by pointing out that a core part of the Savolainen (2008) model remains information seeking and proposes that instead of information being the central core of study, information should be seen as part of social practice suggesting a more appropriate term would be 'information in social practice'. Indeed, Cox (2012) suggests that, in information behaviour models and the Savolainen (2008) model, information activities remain overt and individualistic as opposed to acknowledging that information activities are hidden, tacit and interconnected with other social practices.

7.8 Embodied knowledge

In this study embodied knowledge was identified as a competency often having arisen out of other information practices which were not always overt. For example, Theresa used her embodied knowledge regarding the sugar content of foods identified on the food labels to decide not to purchase and her cookery know-how to adapt recipes. Isobel used her knowledge about foods suitable for a low carbohydrate diet in order to select/adapt recipes to meet her 'rule of thumb'. There is a suggestion that what people know, i.e. embodied knowledge, could also be referred to as embodied information, that is a resource to be used by the individual and or shared (Case & Given, 2016, p. 68). However, Merleau-Ponty explained that all knowledge is embodied. That is if you have knowledge, it must be part of you and thus embodied (Merleau-Ponty, 1962, p. 25; Oerther & Oerther, 2018, p. 820).

Researchers have explored the impact of embodied knowledge on information behaviour. For example, Sanders and Crozier (2018) undertook a meta-synthesis of 14 qualitative studies to explore informal information sources utilised by pregnant women. They found that the women had an 'embodied knowledge base' and used this as a starting point in order to obtain additional relevant information. Similarly, Kneck, Fagerberg, Eriksson, and Lundman (2014) in their study on styles of learning with 13 people with diabetes (8 with T2DM) found that participants had an embodied knowledge which was 'interwoven' with experiential information and theoretical information. Additionally, Kneck (2015) found that learning itself was an 'informal and everyday process' (p. 1). This final point is a reminder that information behaviour is instinctive (Spink, 2010, p. xii), tacit, automatic and part of social practice.

However, in information practice, embodied knowledge is seen as a competency, that is a skill. As with other skills embodied knowledge is developed from other information practices. Once acquired it forms part of someone's everyday practices, as in the case of Victoria who used semi-skimmed milk and William's wife who used spray oil, in order to meet their dietary 'rules of thumb'. The source of the information was unclear, had become embodied and informed their 'rules of thumb'.

7.9 Theoretical contribution

This study is novel in its use of practice theory as the theoretical framework in the exploration of nutrition information practices in people with T2DM. While there is some research exploring nutrition information behaviour, there is a limited research base in the area of nutrition information practices. This study has identified the impact of embodiment on nutrition information practice, the

development of embodied knowledge and its use in information practices and the interconnectedness with other practices. Few studies have made the link between embodiment and practices. While some have identified the importance of embodied knowledge in information practices (see for example Kneck et al., 2014) and the importance of embodiment in self-management (Funa, 2012; Whittemore et al., 2002), few studies have made the link between embodiment and the enactment of nutrition information practices.

There is limited research relating specifically to the ability of people with T2DM to use food labels to make decisions about what to eat. This study identified that many people with T2DM use food labels in order to self-manage, however at the same time the challenges in using food labels (standardisation, need for numeracy skills, needing to be able to interpret both the front of pack information as well as the back of pack information) were exposed. This suggests that food labels are not as valuable a source of information to people with T2DM as research relating to those without T2DM indicates (Croker et al., 2020; Temple, 2020).

There is limited research relating to the information practices involving peer support groups. This study, by using practice theory as the theoretical framework, identified the practice of sharing non-specific information in the peer support group setting. This finding has challenged the accepted approach to information activities which uses the concept of information behaviour to study the way that people interact with information. Information behaviour is individualistic and implies information activities whether active or passive have specific information in mind. However, information practice by its nature of being instinctive, embodied and interconnected with other practices allows the concept of sharing of information to develop. Specifically sharing of non-specific information as to how to live with T2DM. Using information practice as the theoretical framework has exposed the key aspect and yet hidden nature of information practices.

7.10 Recommendations for practice

Consultations with dietitians should take into account the presence of embodied diabetes and knowledge and the hidden and tacit nature of food practices. The assessment process should begin with finding out what patients know already and what they would like to achieve from a consultation in order that practitioners can meet patients where they are and focus on a patient led consultation. In the dietetic clinical encounter the assessment includes finding out about 'meal patterns, lifestyle, likes, and dislikes, food choices and beliefs about different foods' as well as the willingness to change (Gandy, 2019, pp. 718-719). However, a greater focus could be made on food

practices overall in T2DM nutritional consultations (ibid, p. 676). For example, questions about what informs the meal planning, the shopping, the recipe choice, who makes these decisions and who else is part of the food practices could regularly be included in the diet history section of the nutritional assessment. People with T2DM carry embodied knowledge and their own rules of thumb about what foods might be good for their diabetes The wide range of rules of thumb identified in the empirical research study support the current clinical practice of there not being a 'one-size-fits-all' approach (Diabetes UK Nutrition Working Group, 2018 p. 11). However, this may also suggest that people with T2DM may draw on embodied dietary rules that are not 'acceptable or enjoyable' (ibid p. 11) and which may not contribute to their diabetes management. As the literature review and the empirical research study identified, having diabetes and needing to follow a diet for diabetes leads to feelings of control, guilt and stress. Efforts should be made by practitioners to ensure that people with T2DM can follow dietary advice that is 'acceptable and enjoyable' to them and therefore more likely to contribute to their improved dietary control (ibid p. 11). Time and skills are needed to elucidate these aspects as food practices are hidden and tacit and those relating to cooking are unconscious (van Kesteren & Evans, 2020).

Since practices are embodied, skills and time are needed to uncover these, and the information given needs to meet food beliefs and build on the embodied knowledge already held. As dietitians are the only HCP who have specific training in food and nutrition, diabetes services should be reviewed to ensure that dietitians are key in the delivery of nutritional information to people with T2DM and in assisting HCPs such as GPs and nurses to support people with T2DM nutrition information. The dietetic curriculum and training of student dietitians needs to be enhanced to incorporate the concept of embodied diabetes, the importance of nutrition information in being able to self-manage T2DM, the central role that the dietitian has in the delivery of nutrition information and the potential for dietitians to assist other HCPs in helping people with T2DM.

Food labels were identified by the participants as having limited value in supporting their T2DM management. The format of the information being designed to meet the needs of the general population meant that the information was not presented in a way that was usually of value to people with T2DM. Food labels could potentially help people with T2DM to be able to self-manage, however in order to realise their value participants needed to interrogate and undertake extensive calculations. The challenges in being able to understand them led to feelings of disempowerment and lack in confidence in being able to make decisions about what to eat. Services providing information to people with T2DM should enhance their focus on helping people with T2DM to

interpret the information on food labels to help them self-manage. Particularly in understanding the traffic light system and its focus on sugar, fat, saturated fat and salt. The information should clarify that the front of pack traffic light system does not include the amount of carbohydrate in a food item, that the information about sugar does not discriminate between the amount of total sugars and free sugars in a food item and while fat content may be labelled as red, the food item may have other healthy attributes. Many participants carried a belief that sugar was bad for them and focussed their review of food labels and decisions about what to eat based on the amount of sugar in a food item when the amount of sugar in the food item was minimal. More time should be spent on explaining the nutritional value of foods and helping people with T2DM to interpret food labels. The diary approach of gathering information that they come across and bringing this to the next consultation or group session would help in the information to be individualised and delivered in a way that make sense to them.

While those providing nutritional information to people with T2DM should spend more time on clarifying the information on food labels and how the information could be applied to day-to-day food choices, there is also a place for policy makers to review the format of food labels and the information included in them. The use of the colour coding system should be reviewed. The embodied negative meaning of the colour red on a food label may overemphasise the potential unhealthy nature of these foods and promote the feeling of guilt around eating as opposed to enjoyment. Consideration should be given to promoting the inherent nutritional value of a food item including those that are currently labelled as red. For example foods that are labelled red or amber because of their fat content in the current system may contain healthy fats and or other additional nutrients which are considered acceptable within a healthy diet. In these cases the avoidance of such foods may lead to an unnecessarily restrictive diet. The system also appears to emphasise the nutritional value of foods that have little inherent nutritional value. For example, a green label may suggest a food possesses healthy attributes when they may not have any additional nutritional attributes over and above not being high in fat sugar or salt. Consideration should be given to changing the focus on the front of pack label from an emphasis on the amount of fat, sugar and salt to highlighting the nutritional value in order to encourage people to choose foods with inherent nutritional values known to contribute to the consumption of a healthy balanced diet. The value in the peer support sessions in helping people with T2DM to live with their diabetes is worthy of further application to practice. HCPs could consider suggesting attendance to people with T2DM particularly those who are having difficulty in coming to terms with their diabetes and or in applying the dietary advice to their own daily lives. HCPs should be aware of services such as these

available in their area and promote their development with diabetes charities and or with local diabetes services as part of a range of management options. The finding from the systematic review that support sessions that included practical components were effective in helping people to self-manage could be further enhanced. HCPs including dietitians should work alongside charities to enhance the provision of peer support sessions to include sessions from HCPs. While participants were able to access information online such as through Diabetes UK, the discussions in the peer support group setting around their own food provisioning proved beneficial. Group sessions providing cooking skills and/or discussing food preparation could be included in services for people with T2DM.

Although dietitians are the only healthcare professionals who are specifically trained to deliver nutritional advice and information, the current focus is on behaviour change approaches. However these underestimate the important role that information has in being able to self-manage (Johnson & Case, 2012, p. 15). This focus on behaviour change as an approach to dietetic management emphasises the process of dietetic intervention, that is of specific actions taken to help people with T2DM and implies that the action is being 'done to' the patient. While few participants had/recalled that they had a consultation with a dietitian, research suggests that dietetic interventions with T2DM are effective (Siopis et al., 2021) however the approach is not always patient centred and may be directive (Ball et al., 2016). By shifting the focus of the consultation with the dietitian from changing behaviour to the provision of information and/or facilitating people with T2DM to find the information that they need in order to apply this to their own decision making may ensure the contact is patient centred and be more effective in helping people with T2DM to self-manage.

The study uncovered shortcomings in the provision of nutritional information to the participants. While structured education should be offered 'at and around the time of diagnosis, with annual reinforcement and review...evidence-based, and suit[...] the needs of the person' (NICE, 2015), in this study the opportunity had not been made available to many participants. Although figures from the National Diabetes Audit (2020) suggest that 77.5% of people with T2DM were offered structured education in their first year of diagnosis (and just 13.3% attended in that first year), this does not account for the ongoing need for information as identified in this study. Not only had most participants not been referred for structured education (potentially as most were not newly diagnosed), there also did not appear to have been provision made for annual reinforcement and review. Further efforts are needed to ensure that the 'annual reinforcement and review' of nutrition

information is provided and that this is undertaken by an HCP who is trained to do so, i.e. a dietitian and/or an HCP acting with the support of a dietitian.

The term structured education suggests a lack of a flexible approach and a one-way process that may not allow for the uncovering of embodied food practices, embodied knowledge and the potential to share with others who have T2DM. The organisation of structured education sessions should be reviewed to include opportunities to share information between participants and the opportunity to meet up after a period to share experiences. As there appears to be a lack of availability in structured education sessions (despite the National Diabetes Audit, 2020 figures), and lack of annual review, alternative opportunities for people with T2DM to obtain nutrition information should be explored. The arrangement of peer led support groups as identified in this study could be one way to ensure that people with T2DM receive the information they need about how to live with T2DM in the format that they prefer (Cradock et al., 2021; Deakin, 2016, p. 131; Gandy, 2019, pp. 718-719; Meier et al., 2018, p. 210; van Kesteren & Evans, 2020).

In order to find out more about nutrition information for T2DM, participants, particularly Isobel, used their searching and criticality skills in order to identify information that was of value to them. This is a key skill needed across the diabetes. For example, in the early stages of understanding what diabetes is and how best to manage it as well as when someone has had diabetes for a long time and is learning about new dietary approaches that could help with self-management. Being able to critically appraise information is an important skill especially when so many different sources of nutrition information are available. Time within dietetic and /or HCP consultations, structured education sessions and /or peer support group sessions should be given over to discussing sources of information, how to critically appraise the information and to interpret its applicability to the individual situation of someone with T2DM.

Participants found the diary approach beneficial as it motivated them to uncover potential sources of nutrition information and apply these to their food practices. Similarly, Cradock et al. (2021) found that the diary approach helped sensitise participants to potential ideas and actions that could help them manage their T2DM. However, in this current study several participants had experience of and/or were simultaneously keeping a food record. This process of food logging is a common approach in helping people with T2DM in their self-management (Deakin, 2016 page 131). The acceptability of the diary process in the current study suggests that the food-logging approach could be extended to include holistic food and information practices for use by people with T2DM to

encourage and maximise information practice. The information diary could be developed to encourage patients to identify nutritional information. Patients especially those who are struggling to come to terms with diabetes and or are lacking motivation in their diabetes management could be encouraged by practitioners to log nutrition information that they come across that is relevant to them. The approach could also be used to encourage people with T2DM to produce their own information resource as identified by Lloyd et al. (2014) in their study with people with chronic kidney disease and by Whetstone (2013) in their study of information kept by people with T2DM. The process could be further enhanced by being used as a prompt for discussions in consultations with dietitians, in structured education and/or peer support group settings in order to co-create nutrition information that is used.

7.11 Recommendations for further research

There is limited research in the area of information practice and nutrition information practice per se. Further research could explore information practice and nutrition information practice with other long-term conditions and other embodied practices to identify similarities and differences that may be applied to enhance the management of other long-term conditions.

The value in the diary approach in highlighting potential sources of information has been found in other research. St. Jean (2012) and Cradock et al. (2021) also found that the diary approach highlighted information to their participants. As Cradock et al. (2021) also identified, diaries are known to have a therapeutic value (Brinkmann & Kvale, 2015, p. 35; Plummer, 2001, p. 243; Spowart & Nairn, 2014), this raises questions about the potential therapeutic value of diary keeping for people with long term conditions. Further research could explore the use of the unstructured diary to collect embodied practices of people with T2DM and how this could be used to facilitate consultations with practitioners such as dietitians GPs and nurses.

Further research is needed to explore the experiences of people with T2DM with food labels. There may be potential for this to contribute to the formulation of front of pack and back of pack information to enhance the value to people with T2DM. Research into how best to provide education on food labels to people with T2DM is needed to find out how best to support them to be able to apply the information to their own food practices.

The potential for peer support groups to support people with T2DM is worthy of further research.

The characteristics of peer support groups, their value in delivering nutritional information

particularly on food provisioning, understanding food labels, developing critical appraisal skills and their potential in uncovering patient centred ways of managing T2DM is worthy of further research. However as identified in the empirical research study and suggested by Simmons et al. (2013) there is a potential risk in that peer support groups may not be up to date with the latest research. Therefore decisions about leadership, the involvement of HCPs and how best to incorporate these into the services available for people with T2DM could also be explored.

Further research is needed to explore the apparent dissonance between the National Diabetes Audit (2020) figures suggesting that 77.5% of people with T2DM were offered structured education in their first year of diagnosis and the experience of the participants in the current study of not being offered the opportunity. The current provision and makeup of the structured education session could be investigated as to its availability not to just those who are newly diagnosed with diabetes as well as its potential to provide opportunities for learning about food provisioning, food labels and critical appraisal and sharing information.

Since the delivery of services to people with T2DM is multidisciplinary, further research is needed to explore the effectiveness of the current provision of nutrition information. The focus is on delivering this through group education using a structured approach, however this is not available to many and there is limited follow up. While the emphasis should be on the direct involvement of dietitians, this may not be practical within current service levels. Therefore, further research is needed to explore the potential for dietetic services to support other HCPs in the delivery of nutritional information to people with T2DM.

The identification of the importance of critical appraisal skills to people with T2DM in this current study is worthy of further research. This is particularly when applied to information available on the internet, social media and in newspapers especially as research suggests information available from these sources may not always be evidence based (Cooper et al., 2012; Wang et al., 2019; Weymann et al., 2015).

Further research is needed to explore other methods that could help to understand the nutrition information practices of people with T2DM through the greater involvement of the researcher. For example, by including observational elements to the study such as joint shopping trips to observe the food purchase decision making processes and interviews could be undertaken where food provisioning decisions are undertaken.

7.12 Strengths and limitations

This study contributes to a growing number of studies using the theoretical framework of practice theory, the narrative approach in the systematic review and the diary-interview approach in studying nutrition information practices in people with T2DM. The strengths of the study lie in the selection of the methodologies, the use of a narrative approach in the systematic review, the development of the method in the empirical research study and the synergistic nature of the two studies. The use of a systematic review in response to the apparent limited research in the area of nutrition information practice in T2DM supported the study premiss that nutrition information is crucial to the self-management for people with T2DM. The application of a broad inclusion criteria enabled the selection of a wide range of heterogenous studies.

The qualitative methodology used in the empirical research study enabled the uncovering of everyday tacit food and nutrition information practices of people with T2DM. The development of the method through piloting and lay group checking ensured that the process was not burdensome and that participants were able to engage in the research process. The use of the diary approach, as it is known to help identify tacit practices, was a strength. The approach coupled with the interview allowed a review of the diary entries which enabled further understanding of these practices. The selection of practice theory to facilitate analysis of the information activities enabled a deeper understanding and an extension of this to information practice. By using practice theory, this revealed the lived experiences of the participants in their information practices.

There are some improvements that could be made that have the potential to be applied to future studies using these methods. The limitations of the systematic review already discussed in chapter two relate to the specific search terms used, the heterogenous studies almost all of which had quality issues.

There were also strengths and limitations with the methodology of the empirical research study. A key aspect was the selection of a diary to collect data. Participants may have been familiar with the use of a diary as it is often used as a dietetic consultation tool. This familiarity was a strength in that it may have encouraged diary completion. However the experience with having used a food diary may have led to an automatic assumption by those participants that the researcher expected food diary entries. For those who made food diary entries, the researcher was able to utilise the diary-

interview approach to explore what nutrition information had been used to inform their food choices recorded in these parts of their diaries.

Neither the systematic review nor the empirical research study focused on the specific content of the nutritional advice delivered and whether these were within current guidelines. Future studies exploring the nutrition information practices of people with T2DM could analyse and map information that is accessed in order to ascertain the likely sources of evidence-based information.

Although the choice of interview setting was given to participants the interconnectedness of nutrition information practices and food practices could be further explored if interviews were undertaken in participant's own homes along with observational elements to the study (see for example Whetstone, 2013).

While recruitment from peer support groups enabled an in-depth exploration of these as sources of information, in order to enable greater comparative experiences, recruitment could be drawn from a wider range of settings. The delivery of a nutrition talk to peer support groups may have encouraged recruitment particularly of peer support group facilitators and so resulted in an over representation of peer support group facilitators in the sample and potentially discouraged potential participants from taking part. However the recruitment from T2DM support groups may also have resulted in recruitment of participants who were highly engaged in the management of their T2DM.

7.13 Impact of being a dietitian

In the empirical research study several participants commented on the lack of nutritional advice available to them and one said in their interview that they had chosen to take part in the study in order to find out more about nutrition. The researcher being a dietitian may have encouraged participants to take part, as research suggests that participants may take part in research projects in order to access care (Lawton et al., 2003) especially in situations where treatment and information were 'unavailable or difficult to obtain' (Townsend & Cox, 2013). However, being a dietitian may also have prevented participation as people may not have wanted to talk about their nutrition information practices to an HCP who specialises in food and nutrition. Being a dietitian may have influenced the analysis particularly that relating to the value of HCPs to the participants by disregarding these as valid sources of information. However, asking participants directly about HCPs involvement in their nutritional care and using a 'line by line' approach to the analytical process would have protected against this.

Similarly, although one participant was willing to share with the researcher her dietary approach that was outside the current guidelines, other participants may have withheld their dietary approaches from the researcher. While the study was not about what participants ate on a day-to-day basis, many did include information about what they ate in their diaries. Had the researcher not been a dietitian this may not have occurred. However, being aware that the researcher was a dietitian conversely may have led them to restrain their discussions to foods and topics that they felt the researcher would consider appropriate for someone with T2DM.

None of the participants in the empirical research study were known to the researcher in their previous role as a community dietitian or in their current role as a lecturer in dietetics. The researcher was not involved in the direct clinical care of any of the participants. However as a registered dietitian the researcher was aware of the importance of following their registration body's guidance and the need to ensure that participants obtained the nutritional care that they needed.

dietitian

7.14 Conclusion

This study has reinforced the importance of nutrition information to people with T2DM. It adds to the research base relating to the use of practice theory and its elements of meaning, materials and competencies to information activities particularly that relating to T2DM and nutrition information. The study using practice theory and the diary-interview approach exposed the nutrition information practices of people with T2DM. Information practices were found to be embodied, relied on embodied knowledge and were interconnected and entangled with other practices particularly food related practices. This study has challenged the current body of research relating to information activity and proposes information practice as a concept that could be used to explore information activities further. Most research in this area uses information behaviour as a framework and does not specifically explore nutrition information activities. Indeed, the study has added to the research on information activities, in general, to those undertaken by people with long term conditions and relating to nutrition. The study has identified that nutrition information practice is interconnected with food practices; that practices are embodied; that embodiment of diabetes is needed before people with T2DM can self-manage; and that information practices including sharing information with peers can assist in the embodiment process. However, the study has also highlighted that information designed to assist people to self-manage and make decisions about what to eat such as

food labels are challenging for people with T2DM to use and that nutrition information services are in short supply. People with T2DM need information on what to eat and how to live with T2DM.

The study underlines the elements of practice theory (meaning, competency and materials) and that these elements are worthy of further research with other long-term conditions. The finding that nutrition information practice is embodied could be used to enhance the dietetic consultation with people with T2DM ensuring that it is patient led and the use of a nutrition information diary in consultations may assist with this. The limited availability of nutrition information services suggests that further exploration is needed as to what is currently available to people with T2DM. While food labels were found to be challenging in their application to deciding what to eat, peer support groups were a significant source of information for this group of participants. Further research should be undertaken to explore the experiences of the use of food labels, the potential value of peer support groups amongst people with T2DM and how to ensure that people with T2DM obtain the nutrition information that they need.

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9 Appendices

9.1 Appendix 1: Description of and rationale for databases used

Database and reference 29 th March 2021	Description	Rationale for usage
PubMed http://www.nlm.nih.go v	'PubMed® comprises more than 32 million citations for biomedical literature from MEDLINE, life science journals, and online books.'	The topics cited are likely to be relevant to the review. PubMed may contain articles before they are indexed by MEDLINE
CINAHL https://www.ebsco.co m/products/research- databases/cinahl- complete	Designed to meet the information needs of nurses and allied health professionals, and coverage includes consumer health, health sciences	The researcher is an allied health professional and the topic of research relates to the coverage of the database
PsycINFO https://www.apa.org/pubs/databases/psycinfo	Produced by the American Psychological Association	Psychology of information activities may relate to area of research
Google Scholar https://scholar.google.com/	Enables a broad search of scholarly literature in a wide range of publications	Potential to identify studies that are outside the remit of the other databases
SCOPUS http://www.scopus.co m	Largest abstraction and citation database of research literature and quality web sources	The data base covers the fields of science, technology, medicine, social sciences, and arts and humanities and so assists in identifying studies outside the reach of the other selected databases

9.2 Appendix 2: Search Terms, filters, limits and search strategy

Search terms

("Type 2 Diabetes" OR Diabetes OR Diabetic OR "Type 2 diabetic")

AND

("Information behaviour" OR "Information behavior" OR "Health information behaviour" OR "Health information behavior" OR "Consumer information behavior" OR "Consumer information behavior" OR "Human information behavior" OR "Human information behavior" OR "Information practice" OR "Information work" OR "information Communication" OR "information sharing" OR "Information seeking behavior" OR "Health information seeking behavior" OR "Health information seeking" OR "Information access" OR "Information need" OR "Information use" OR "Health information processing" OR information)

AND

(Passive OR active OR proactive OR avoidance)

AND

(Diet OR Dietary OR Dietetic OR Dietitian OR Dietician OR Nutrition OR nutritionist OR "Nutritional therapist" OR Cook OR cooking OR Cookery OR Cookbook OR Recipe OR Food OR Eat OR eating OR Weight OR obesity OR "Body mass index" OR BMI OR "healthy living" OR lifestyle)

Filters and limits

The data base searches were set to only include articles that were published in English, that referred to humans and to adults

No time limits were set for the data base searches

Search Strategy

The search strategy for PubMed with results for each search state is set out below

Medline

Stag	Query	Filters	Search Details	Results
e				
1	"Type 2 Diabetes" OR Diabetes OR Diabetic OR "Type 2 diabetic"	Humans, English, Adult: 19+ years, from 1000/1/1 - 2021/3/2 9	("Type 2 Diabetes"[All Fields] OR ("diabete"[All Fields] OR "diabetes mellitus"[MeSH Terms] OR ("diabetes"[All Fields] AND "mellitus"[All Fields]) OR "diabetes mellitus"[All Fields] OR "diabetes"[All Fields] OR "diabetes insipidus"[MeSH Terms] OR ("diabetes"[All Fields] AND "insipidus"[All Fields]) OR "diabetes insipidus"[All Fields] OR "diabetic"[All Fields] OR "diabetics"[All Fields] OR "diabetes mellitus"[MeSH Terms] OR ("diabetes"[All Fields] AND "mellitus"[All Fields]) OR "diabetes mellitus"[All Fields] OR "diabetes"[All Fields] OR "diabetes insipidus"[MeSH Terms] OR ("diabetes"[All Fields] AND "insipidus"[All Fields]) OR "diabetes insipidus"[All Fields] OR "diabetic"[All Fields] OR "diabetics"[All Fields]) OR "diabetes insipidus"[All Fields]) OR "Type 2 diabetic"[All Fields]) AND ((humans[Filter]) AND (1000/1/1:2021/3/29[pdat]) AND (english[Filter]) AND (alladult[Filter]))	297,759

2	"Information behaviour" OR	Humans,	("Information behaviour"[All Fields] OR "Information behavior"[All Fields] OR	470,815
	"Information behavior" OR "Health	English,	"Health information behaviour"[All Fields] OR "Health information	
	information behaviour" OR "Health	Adult: 19+	behavior"[All Fields] OR (("consumable"[All Fields] OR "consumables"[All	
	information behavior" OR "Consumer	years,	Fields] OR "consume"[All Fields] OR "consumed"[All Fields] OR "consumer"[All	
	information behaviour" OR "Consumer	from	Fields] OR "consumer s"[All Fields] OR "consumers"[All Fields] OR	
	information behavior" OR "Human	1000/1/1	"consumes"[All Fields] OR "consuming"[All Fields]) AND ("inform"[All Fields]	
	information behaviour" OR "Human	-	OR "informal"[All Fields] OR "informality"[All Fields] OR "informally"[All Fields]	
	information behavior" OR "Information	2021/3/2	OR "informant"[All Fields] OR "informant s"[All Fields] OR "informants"[All	
	practice" OR "Information work" OR	9	Fields] OR "information" [All Fields] OR "information s" [All Fields] OR	
	"information Communication" OR		"informational"[All Fields] OR "informations"[All Fields] OR "informative"[All	
	"information sharing" OR "Information		Fields] OR "informatively"[All Fields] OR "informativeness"[All Fields] OR	
	seeking behaviour" OR "Information		"informativity"[All Fields] OR "informed"[All Fields] OR "informer"[All Fields]	
	seeking behavior" OR "Health		OR "informers"[All Fields] OR "informing"[All Fields] OR "informs"[All Fields])	
	information seeking behaviour" OR		AND ("behavior"[MeSH Terms] OR "behavior"[All Fields] OR "behavioral"[All	
	"Health information seeking behavior"		Fields] OR "behavioural"[All Fields] OR "behavior s"[All Fields] OR	
	OR "Health information seeking" OR		"behaviorally"[All Fields] OR "behaviour"[All Fields] OR "behaviourally"[All	
	"Information access" OR "Information		Fields] OR "behaviours"[All Fields] OR "behaviors"[All Fields] OR "pattern"[All	
	need" OR "Information use" OR "Health		Fields] OR "pattern s"[All Fields] OR "patternability"[All Fields] OR	
	information processing" OR information		"patternable"[All Fields] OR "patterned"[All Fields] OR "patterning"[All Fields]	
			OR "patternings"[All Fields] OR "patterns"[All Fields])) OR (("consumable"[All	
			Fields] OR "consumables"[All Fields] OR "consume"[All Fields] OR	
			"consumed"[All Fields] OR "consumer"[All Fields] OR "consumer s"[All Fields]	
			OR "consumers"[All Fields] OR "consumes"[All Fields] OR "consuming"[All	
			Fields]) AND ("inf behav"[Journal] OR ("information"[All Fields] AND	
			"behavior"[All Fields]) OR "Information behavior"[All Fields])) OR (("human	
			s"[All Fields] OR "humans"[MeSH Terms] OR "humans"[All Fields] OR	
			"human"[All Fields]) AND ("inform"[All Fields] OR "informal"[All Fields] OR	
			"informality"[All Fields] OR "informally"[All Fields] OR "informant"[All Fields]	
			OR "informant s"[All Fields] OR "informants"[All Fields] OR "information"[All	

Fields] OR "information s"[All Fields] OR "informational"[All Fields] OR "informations"[All Fields] OR "informative"[All Fields] OR "informatively"[All Fields] OR "informativeness" [All Fields] OR "informativity" [All Fields] OR "informed"[All Fields] OR "informer"[All Fields] OR "informers"[All Fields] OR "informing"[All Fields] OR "informs"[All Fields]) AND ("behavior"[MeSH Terms] OR "behavior" [All Fields] OR "behavioral" [All Fields] OR "behavioural" [All Fields] OR "behavior s"[All Fields] OR "behaviorally"[All Fields] OR "behaviour"[All Fields] OR "behaviourally"[All Fields] OR "behaviours"[All Fields] OR "behaviors" [All Fields] OR "pattern" [All Fields] OR "pattern s" [All Fields] OR "patternability"[All Fields] OR "patternable"[All Fields] OR "patterned"[All Fields] OR "patterning"[All Fields] OR "patternings"[All Fields] OR "patterns" [All Fields])) OR "Human information behavior" [All Fields] OR "Information practice"[All Fields] OR "Information work"[All Fields] OR "information Communication"[All Fields] OR "information sharing"[All Fields] OR "Information seeking behaviour" [All Fields] OR "Information seeking behavior"[All Fields] OR "Health information seeking behaviour"[All Fields] OR "Health information seeking behavior"[All Fields] OR "Health information seeking"[All Fields] OR "Information access"[All Fields] OR "Information need"[All Fields] OR "Information use"[All Fields] OR "Health information processing"[All Fields] OR ("inform"[All Fields] OR "informal"[All Fields] OR "informality"[All Fields] OR "informally"[All Fields] OR "informant"[All Fields] OR "informant s"[All Fields] OR "informants"[All Fields] OR "information"[All Fields] OR "information s"[All Fields] OR "informational"[All Fields] OR "informations" [All Fields] OR "informative" [All Fields] OR "informatively" [All Fields] OR "informativeness" [All Fields] OR "informativity" [All Fields] OR "informed"[All Fields] OR "informer"[All Fields] OR "informers"[All Fields] OR "informing"[All Fields] OR "informs"[All Fields])) AND ((humans[Filter]) AND (1000/1/1:2021/3/29[pdat]) AND (english[Filter]) AND (alladult[Filter]))

3	Passive OR active OR proactive OR	Humans,	("passive"[All Fields] OR "passively"[All Fields] OR "passives"[All Fields] OR	1,020,51
	avoidance	English,	("activable"[All Fields] OR "activate"[All Fields] OR "activated"[All Fields] OR	7
		Adult: 19+	"activates"[All Fields] OR "activating"[All Fields] OR "activation"[All Fields] OR	
		years,	"activations"[All Fields] OR "activator"[All Fields] OR "activator s"[All Fields]	
		from	OR "activators"[All Fields] OR "active"[All Fields] OR "actived"[All Fields] OR	
		1000/1/1	"actively"[All Fields] OR "actives"[All Fields] OR "activities"[All Fields] OR	
		-	"activity s"[All Fields] OR "activitys"[All Fields] OR "motor activity"[MeSH	
		2021/3/2	Terms] OR ("motor"[All Fields] AND "activity"[All Fields]) OR "motor	
		9	activity"[All Fields] OR "activity"[All Fields]) OR ("proactive"[All Fields] OR	
			"proactively"[All Fields] OR "proactivity"[All Fields]) OR ("avoid"[All Fields] OR	
			"avoidability"[All Fields] OR "avoidable"[All Fields] OR "avoidance"[All Fields]	
			OR "avoidances"[All Fields] OR "avoidant"[All Fields] OR "avoidants"[All Fields]	
			OR "avoided"[All Fields] OR "avoider"[All Fields] OR "avoiders"[All Fields] OR	
			"avoiding"[All Fields] OR "avoids"[All Fields])) AND ((humans[Filter]) AND	
			(1000/1/1:2021/3/29[pdat]) AND (english[Filter]) AND (alladult[Filter]))	

4	Diet OR Dietary OR Dietetic OR Dietitian	Humans,	("diet"[MeSH Terms] OR "diet"[All Fields] OR ("diet"[MeSH Terms] OR	889,600
	OR Dietician OR Nutrition OR nutritionist	English,	"diet"[All Fields] OR "dietary"[All Fields] OR "dietaries"[All Fields]) OR	
	OR "Nutritional therapist" OR Cook OR	Adult: 19+	("dietetics"[MeSH Terms] OR "dietetics"[All Fields] OR "dietetic"[All Fields]) OR	
	cooking OR Cookery OR Cookbook OR	years,	("dietitian s"[All Fields] OR "nutritionists"[MeSH Terms] OR "nutritionists"[All	
	Recipe OR Food OR Eat OR eating OR	from	Fields] OR "dietitian"[All Fields] OR "dietitians"[All Fields]) OR	
	Weight OR obesity OR "Body mass	1000/1/1	("nutritionists"[MeSH Terms] OR "nutritionists"[All Fields] OR "dietician"[All	
	index" OR BMI OR "healthy living" OR	-	Fields] OR "dieticians"[All Fields]) OR ("nutrition s"[All Fields] OR "nutritional	
	lifestyle	2021/3/2	status"[MeSH Terms] OR ("nutritional"[All Fields] AND "status"[All Fields]) OR	
		9	"nutritional status"[All Fields] OR "nutrition"[All Fields] OR "nutritional	
			sciences"[MeSH Terms] OR ("nutritional"[All Fields] AND "sciences"[All Fields])	
			OR "nutritional sciences"[All Fields] OR "nutritional"[All Fields] OR	
			"nutritionals"[All Fields] OR "nutritions"[All Fields] OR "nutritive"[All Fields])	
			OR ("nutritionist s"[All Fields] OR "nutritionists"[MeSH Terms] OR	
			"nutritionists"[All Fields] OR "nutritionist"[All Fields]) OR "Nutritional	
			therapist"[All Fields] OR ("cooking"[MeSH Terms] OR "cooking"[All Fields] OR	
			"cook"[All Fields]) OR ("cooking"[MeSH Terms] OR "cooking"[All Fields] OR	
			"cooked"[All Fields] OR "cooks"[All Fields]) OR ("cooking"[MeSH Terms] OR	
			"cooking"[All Fields] OR "cookery"[All Fields]) OR ("cookbook"[All Fields] OR	
			"cookbooks"[All Fields]) OR ("recipe"[All Fields] OR "recipes"[All Fields]) OR	
			("food"[MeSH Terms] OR "food"[All Fields]) OR "Eat"[All Fields] OR	
			("eating"[MeSH Terms] OR "eating"[All Fields]) OR ("weight s"[All Fields] OR	
			"weighted"[All Fields] OR "weighting"[All Fields] OR "weightings"[All Fields] OR	
			"weights and measures"[MeSH Terms] OR ("weights"[All Fields] AND	
			"measures"[All Fields]) OR "weights and measures"[All Fields] OR "weight"[All	
			Fields] OR "body weight"[MeSH Terms] OR ("body"[All Fields] AND	
			"weight"[All Fields]) OR "body weight"[All Fields] OR "weights"[All Fields]) OR	
			("obeses"[All Fields] OR "obesity"[MeSH Terms] OR "obesity"[All Fields] OR	
			"obese"[All Fields] OR "obesities"[All Fields] OR "obesity s"[All Fields]) OR	
			"Body mass index"[All Fields] OR "BMI"[All Fields] OR "healthy living"[All	

	Fields] OR ("life style"[MeSH Terms] OR ("life"[All Fields] AND "style"[All	
	Fields]) OR "life style"[All Fields] OR "lifestyle"[All Fields] OR "lifestyles"[All	
	Fields])) AND ((humans[Filter]) AND (1000/1/1:2021/3/29[pdat]) AND	
	(english[Filter]) AND (alladult[Filter]))	

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(1000/1/1:2021/3/29[pdat]) AND
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Dietitian OR Dietician OR Nutrition OR
nutritionist OR "Nutritional therapist"
OR Cook OR cooking OR Cookery OR
Cookbook OR Recipe OR Food OR Eat OR
eating OR Weight OR obesity OR "Body
mass index" OR BMI OR "healthy living"
OR lifestyle AND ((humans[Filter]) AND
(1000/1/1:2021/3/29[pdat]) AND
(english[Filter]) AND (alladult[Filter])))

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Fields])) AND ("humans"[MeSH Terms] AND 1000/01/01:2021/03/29[Date -
Publication] AND "english"[Language] AND "adult"[MeSH Terms]))) AND
((humans[Filter]) AND (1000/1/1:2021/3/29[pdat]) AND (english[Filter]) AND
(alladult[Filter]))

9.3 Appendix 3: Systematic review data extraction tables

Quantitative studies

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
Ball et al. 2012	Cross- sectional study (questionnai re)	Members of Diabetes Australia Queensland (DAQ) with T2DM	Australi a	939	Under 25 to over 75	f=434, m=505	T2DM	To examine the perceptions of people with T2DM of the nutrition care provided by GPs	Less than half had received nutrition care from their GP although there was a high level of satisfaction the care may not be effective	People: GPs, Written information: on nutrition and T2DM
Byrne et al. 2017	Retrospecti ve review of clinical outcomes	Patients attending group education programme with cooking skills component	USA	155	64.3+/- 7.2	f=6, m=149	T2DM	To examine the relationship between attendance at group education among veterans with T2DM and clinical outcomes (HbA1c and blood pressure)	Effectiveness of a programme that includes the development of skills	People: Group education with cooking skills component Written information: Recipes, handouts

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
Fitzgerald et al. 2008	Quantitative questionnai re	Those with cultural ties to Latin America from community settings in Connecticut	USA	201	T2DM 50.60+/- 6.90	not given	100 T2DM	To examine the associations of nutrition knowledge, food label use and food intake among Latinas with and without' T2DM.	Seeing a dietitian in those with T2DM encouraged the use of food labels, but knowledge in both those with T2DM and without T2DM was linked to using food labels to choose healthy foods.	People: Dietitian, Written: food labels
Gray et al. 2014	Cross- sectional study (questionnai re and FFQ)	University of South Australia Adelaide, Diabetes Centre Adelaide, the Royal Adelaide Hospital, Adelaide,	Australi a	124 T2D M	59.9+/-11	f=65, m=86	T2DM	To describe the knowledge and beliefs of health risks associated with a high sodium diet in a population with diabetes and their ability to use food labelling information to choose lower sodium items	Most participants read food labels for sodium content, men had a lower sodium intake,	Written information: Food labels

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
		South Australia								
Herrejon, et al. 2009	Quantitative questionnai re and impact evaluation	People who accessed the website	USA	104	20-84	Unclear -of the original 404 76.2% were female	Unclear	To develop an easy-to- use website that provided accurate and appropriate information about diet and diabetes management in an interactive format that was widely accessible	People who chose to use the website wanted to learn about T2DM as either they or their family or friends had T2DM. The interactive aspects of website were used more frequently and knowledge improved with success attempts.	Media: Interactive website
Kessler & Wunderlich 1999	Cross- sectional study (questionnai re)	Participants attending the American Diabetes Association patient	USA	190	<30->74	f=112, m=78	T1DM and T2DM (Majority)	To explore if there is a link between dietary knowledge, use of food labels, health status and health behaviours with a focus on the newly developed Nutritional	Food label use is higher amongst those who have diabetes, and an understanding of them is higher in those who have seen a diabetes HCP, however knowledge	People: HCPs Written Information: Food labels

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
		education programme s.						Facts information and its use by people with diabetes.	about the difference between sugar and carbohydrate is low	
Martins et al. 2014	Before and after questionnai re (quasi experiment al)	Attendees at a carbohydrat e counting course held at the hospital study site	Brazil	21	Mean age 60	f=16, m=5	T2DM	To assess T2DM patients' adhesion to carbohydrate counting as well as to identify habit changes and the method's applicability.	The HbA1C reduce significantly 1 year after having attended a 4 hour course on diet and diabetes, overall understanding improved despite ongoing difficulties in comprehending certain aspects of the diet	People: Group education
Pinto & Braz 2015	Cross- sectional study (questionnai re)	Diabetes clinic attendees	Portugal	66	47-75	F=29, m=37	T2DM	'Association between clinical characteristics and perceptions about barriers to following a diet plan recommended by a dietitian'	While older patients had a lower BMI and better diabetes control they appeared to be more confused as to how to	People: Dietitian

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
									manage their diet and diabetes	
Searle & Ready 1991	Cross- sectional study (questionnai re)	Randomly selected people with T2DM recorded in the provincial records	Canada	479	30 to over 70	f=249, m=227	T2DM	To assess the potential for an exercise and weight control program for persons with type 2 diabetes	Although 2/3 had advice from a dietitian 2/3 sought additional advice on a range of topics, 60% in weight loss, 50% healthy eating and 25% on food labels	People: Dietitians, hospital doctors, Written Information: meal plans, cookbooks, food labels
Waki et al. 2015	Quantitative outcomes before and after	From those who had taken part in the earlier trial of the online food log	Japan	5	58.6+/-4.1	f=1, m=4	T2DM	To determine if usability and compliance of the DialBetics-assisted-by-FoodLog had improved from the previous version with the addition of a photo app	When the app provided useful information, the use of the app helped to reduce HbA1c,	Media: Online Food Log

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
Waller & Tzeng. 2011	Cross- sectional study (questionnai re)	Urban African American churches in Michigan and Ohio	USA	60	38-82	f=29, m=60	T2DM	To determine the knowledge of Glycaemic Index (GI) and the impact of attending education sessions amongst African Americans with T2DM	73% had attended an education session, however of these only 50% had received guidance on GI, where this had been provided there was a greater knowledge and ability to apply the information	People: Group education
Watson & DuFourd 1992	Cross- sectional study (questionnai re)	Via nurses and nutritionists attending a regional Diabetes Control Program	USA	101	44-65 (5 over 65 and 11 below 44)	NR	T2DM	To determine the perceived and actual level of knowledge of diet by individuals with T2DM with different demographic variables.	The perception of knowledge was similar to actual knowledge, those who had not had diabetes education lacked knowledge.	People: Group education

Qualitative studies

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
Albright 1994	Qualitative interviews	Via physicians who practice in a private, non-profit community hospital	USA	20	65-85	f=18, m=2	T2DM	To explore the dietary habits of overweight elderly people with T2DM that they are engaged in the management of a dietary weight loss regimen and the social psychological processes	Information given was either overwhelming or was not given at all	People: HCPs, Written Information: General written info, exchange lists
Ball et al. 2015	Longitudinal qualitative 3 interviews after recruitment	Members of Diabetes Australia Queensland (DAQ) who had type 2 diabetes	Australi a	10	27-74	f=7	T2DM	The perceptions of people newly diagnosed with T2DM on the nutrition care from HCPs.	Information from HCPs was overwhelming and conflicting with insufficient time allowed in consultations to understand and process.	People: HCPs
Ball et al. 2016	Qualitative telephone interviews	members of Diabetes Australia Queensland	Australi a	10	27-74	f=7	T2DM	Perceptions of newly diagnosed people with T2DM on the nutrition	Seeing a dietitian gave more confidence but the interactions tended to be	People: Dietitian

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
		(DAQ) who						care received from a	directional and not	
		had type 2						dietitian	individualised.	
		diabetes								
		Purposive								
		sampling								
		from those								People: Spousal
	Qualitative,	registered						To determine how		support
	focus	with the						marital relationships,		Written
	groups	university						influence changes in	Importance of involving	information:
Beverly et	including	diabetes	USA	60	51-81	f=30, m=30	T2DM	behaviour related to	spouses in supporting	books, magazines,
al. 2008	those with	service,				,		healthy eating in middle	people with T2DM	newsletters,
	T2DM and	diabetes						aged and older adults		newspapers
	their	community,						with type 2 diabetes.		Media: television,
	spouses	community						.,,,		internet
		settings and								
		broadcast								
		media.								

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
Breland et al. 2013	Qualitative - four focus groups with black and Latino adults	Community of East Harlem New York	USA	37	27-80	f=27, m=10	Diabetes	To identify the knowledge about diabetes of those living in East Harlem, their attitudes, behaviours, motivators and barriers to healthy eating.	Abstract and sporadic advice that was not individualised	People: HCPs
Cradock et al.,2021	Qualitative Design probe and reflective diary	CROI CLANN (10 week MDT lifestyle intervention program) at the Croi Centre, Galway and the Diabetes Centre	Ireland	18	25-65	F=8, m=10	T2DM	By using a design which enables participants with T2DM to self-document and reflect on their daily lives in order to gain insight to develop an artefact to support diet and physical activity behaviour changes.		Written information: Design probe and reflective diary

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
		University Hospital								
Lawrence et al. 2017	Three qualitative discussion groups	From non- communica ble diseases community using a range of recruitment methods	New Zealand	12	46-69 (Mean 60)	f=7, m=5	Self-identified as Pre (n=2) or T2DM (n=10)	To gain a better understanding of common dietary perceptions held by NZ adults with pre-diabetes or diabetes	Participants used a wide range of sources of information with varying experiences to help them manage their diabetes. They needed information on cooking, using food labels and eating out.	People:HCPs, Family, their body, charitable organisations Written information: Food labels Media: broad cast media, ,
Lee et al. 2016	Qualitative focus groups	Public safety-net health system	USA	34	53.8+/- 7.5	m=34	T2DM	What are the perceived barriers to healthy eating in non-Hispanic black men living with T2DM	Advice given by HCPs did not take into account traditional food preferences	People: HCPs,

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
		serving a metropolita n area						and the dietary strategies used by non-Hispanic black men to promote healthy eating.		
Matpady et al., 2020	Qualitative interviews	Following completion of the Diabetes self-managemen t questionnai re at a health centre	India	35	Group A 47.7 (+/- 9.4) group B 54.2 (+/- 6.6)	f=15, m=20	T2DM	To explore the concepts and themes that drive understanding of knowledge, current dietary practices of diabetics, and the barriers and enablers for dietary self-care management	Knowledge was an enabler, and lack and low health literacy were barriers. Minimal sporadic advice was a barrier while an enabler was advice from an HCP. But the advice needs to be tailored.	People: Social network, friends, peers, and family members, relatives who are health professionals, HCPs Media: television shows and commercials.
Meyfroidt et al. 2013	Qualitative utilising six focus groups	Medical settings (community health	Belgium	21	41 to 85	f=7, m=14	T2DM with an HbA1c above 140 mg/dL (6.5%). One patient was not aware that he had T2DM	How patients with T2DM use information sources, how they actively seek information and passively	Participants used a wide range of sources of information even when they had diabetes for	People: HCPs GPs dietitians, family, friends, Media: television,

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
		centre, medical practices) in the Capital.						receive information and what problems they encounter as they search for information on the diet for diabetes.	some time and needed ongoing advice about how to manage their diet. Information from GP and dietitian were considered the most valuable and many indicated a preference for group sessions	internet.
Miller at al. 1997	Postal questionnai re followed by focus group or in- depth interview (note question is not included	Advertisem ents in the newspaper and on television from a rural community in USA	USA	27	51+/-6.3	f27	T2DM	Attitudes towards, ability to use, barriers to using food labels in women with T2DM in order to find out how they want food label information communicated to them.	Participants found using food labels to help them make decisions about what to eat difficult, they did not understand % energy, the difference between saturated and unsaturated fat and between carbohydrate and sugar.	Written information: Food labels-nutrition facts panels General written information

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
	in the findings)									
Mphwanthe et al 2021	Qualitative focus groups and eco-map	Purposive recruitment from participants taking part in a larger study in urban and semi-urban hospitals	Malawi	39	Urban: 57.6 +/- 8.3, non- urban 53.1.+/-	f=21, m=18	T2DM	To qualitatively assess patient/client barriers and facilitators to achieving healthy diet and physical activity to support T2DM selfmanagement in adult Malawians	Information given by HCPs was inconsistent and peer support groups enabled the sharing of information	People: HCPs and peer support groups
Murrock et al. 2013	Qualitative using focus groups and phenomeno logy	African American women attending a family practice centre at an	USA	24	19-84	f24	T2DM	To explore the challenges of dietary management in the context of daily routines, family roles, and responsibilities of African American women with diabetes	Basic advice had been provided by a dietitian and or GP, but this did not give them flexibility to be able to adapt their diets when eating with family and friends	People: HCPs, doctor, dietitian, group education

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
		urban hospital via flyers and the dietitian								
Scott et al.1997	Qualitative interviews	General practice and outpatient diabetes clinic	UK	24	Mean age, West Indian 57, White British 56	not recorded	T2DM	To investigate the health beliefs and service use experience of West Indian and white British people with T2DM	They did not get the advice that took into account their traditional foods and found it difficult to apply the advice they had been given to their decisions about what to eat.	People: HCPs, Written Information: General written information, recipes
Wermeling et al. (2014)	Qualitative interviews	Primary care practices, self-help groups, local clinics and the	German y	35	35-77	f=16, m=19	T2DM	To explore the Type 2 diabetes patient's perception of dietary counselling by GPs.	While the GP was key in providing guidance on how to manage their diet and diabetes, often this did not take into account their cultural context.	People: GPs

Name	Design/ method	Recruitmen t setting	country	n	Age in years	Sex: No. of each	Type of Diabetes	Focus/aims	Theme	Nutrition information sources identified in the studies (i.e. materials) categorised into People/Written Information/Media
		wider local								information/wiedia
		community								

Mixed methods studies

										Nutrition
	Design/	Recruitment				Sex No of	Torre of Dishers	Farma /alima	T l	information
Name	method setting		country	n	Age	each	Type of Diabetes	Focus/aims	Theme	sources identified
										in the studies (i.e.

	Qualitat									materials) categorised into People/Written Information/Media
Frandsen & Kristensen 2002	ive focus groups with people with T2DM receivin	France, Germany, Spain, UK, USA.	France, German y, Spain, UK, USA.	123	45-60	f=64, m=59	T2DM	Factors affecting the compliance of type 2 diabetes with diet and drug therapy, including information sources	Majority were dissatisfied with the information they had received, more so those from Spain	People: Doctors/pharmacy, diabetes organisations Written Information: newspapers, magazines, .

9.4 Appendix 4: Critical appraisal

Key to colour coding:

	RAG rating		not applicable		No or few concerns		
			some concerns		major concern	S	
Qualitative studies	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?	Do the collected data allow to address the research question (objective)?	1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?	 Is the process for analyzing qualitative data relevant to address the research question (objective)? 	3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?	4. Is appropriate consideration given to how findings relate to researchers' influence, e.g. through their interactions with participants?	Comments relevant to amber or red RAG rating
							Small study, mainly female, higher economic income and number of black participants than the US population. However, findings concur
							with other studies. The researchers comment that they used an
							interview schedule to minimise bias of the investigator. Ethics is not
Albright							reported but the study was explained to participants. It is not clear if
1994							any participants chose not to take part.

				Small study. The authors comment that there was not a direct analysis
				of dietary changes. However, findings are linked with research. While
				telephone interviews limited observation of non-verbal cues, this also
Ball et al.				allowed recruitment of participants from a wider geographical area. It
2015				is not clear if there were any or no dropouts .
				Small study. The authors comment that there was not a direct analysis
				of dietary changes. However, findings are linked with research. While
				telephone interviews limited observation of non- verbal cues, this also
Ball et al.				allowed recruitment of participants from a wider geographical area. It
2016				is not clear if there were any or no dropouts.
_				
Beverly et				The authors comment that convenience sampling limits the
al. 2008				transferability of their study.
				Small sample size, recruited from one neighbourhood with more
Breland et				women than men (which they state is not unusual) and opinions may
al. 2013				not be the same as those who did not attend .
				The authors suggest limitations as being the self-report nature, the
				data being limited by engagement in the data collection process and
				propose an improvement as being interviewing participants after the
Cradock et				28 days rather than daily data collections. The role of or impact of the
al., 2021				research team is not considered.
				Despite confirmations some participants did not participate in focus
Lawrence et				groups leading to participant numbers of 3 or less, so these are
al. 2017				referred to as group interviews.
ui. 2017				referred to as group interviews.
				Small sample size, homogeneous group so cannot be generalised
				beyond non-Hispanic black men. Although a quantitative
Lee et al.				questionnaire was used, the findings are not reported in this study.
2016				questionnane was used, the infulligs are not reported in this study.
2010				

Matpady et al., 2020			We don't have full details of recruitment. Authors suggest that focus groups would have been more effective in identifying the themes as the food practices are complex .
Meyfroidt et al. 2013			One patient did not know they had diabetes and one of the sessions was attended by just one patient, the patients were recruited from just one setting primary care and the population had slightly more men in it than the general Belgian population.
Miller at al. 1997			While the study had ethics approval there is no mention of how the women gave consent. There is no evidence of the use of the written questionnaire in the analysis.
Mphwanthe et al 2021			Recruitment was purposive to match participants in a larger study, rather than to the Malawian population.
Murrock et al. 2013			Limitations relating to focus groups, recruitment from one setting limiting transferability.
Scott et al.1997			Details of consent and full details of analytic approach are not reported. Sex of participants is not recorded.
Wermeling et al. 2014			The recruitment process is unclear and we do not hear the voice of the researcher(s), their discipline, the use of field notes, their decision making in the study.

·							
Quantitative non- randomized Byrne et al.	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?	Do the collected data allow address the research question (objective)?	1. Are participants (organisations) recruited in a way that minimizes selection bias?	2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention	3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?	Comments relevant to amber or red RAG rating
2017 (Cohort)							The completeness of the data is not reported, data on confounding variables exercise and medication were not collected.
Fitzgerald et al. 2008 (Case- control)							We do not know the full sample size. Participants were asked to self-report their diabetes.

Gray et al.			
2014 (Cross-		-	The authors suggest that there may have been an issue with the
sectional)		ti	ming of the urine sample.
Herrejon, et			
al. 2009		,	We don't know how many of the final group had diabetes or were
(Cohort)		p	artner or carer.
Kessler &			
Wunderlich.			
1999 (Cross-			
sectional)		,	We do not know how many participants had T2DM.
Martins et			The number who were lost to follow- up are not reported and the
al. 2014		in	npact of medication on HbA1c and potential weight change is not
(Cohort)			onsidered.
Pinto & Braz			
2015 (Cross-		-	The authors say they did not control for pharmacotherapy or
sectional)		m	nobility.
Searle &			
Ready 1991			
(Cross-			
sectional)			Assumptions made on type of diabetes based on age and treatment.
Waki et al.			· · · · · · · · · · · · · · · · · · ·
2015			
(Cohort)			
Waller &		_	This was a silet study a second second second Manda as t
Tzeng 2011			This was a pilot study, a convenience sample was used. We do not
(Cross-			now how many refused to complete. Total potential population from
sectional)		W	hich the sample was recruited was 5-600.
Watson &			
DuFourd			
1992 (Cross-			
sectional)			A convenience sample was used.
			•

Quantitative	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?	Do the collected data allow address the research question (objective)?	1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	2. Is the sample representative of the population understudy?	3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?	4. Is there an acceptable response rate (60% or above)?	Comments relevant to amber or red RAG rating
descriptive Ball et al 2012 (cross-	Are . met.	Do	1. Is aspe	2. Is	3. Aı	4. Is	Although response rate was 11% there were 939
sectional)							respondents.

Mixed Methods	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?	Do the collected data allow address the research question (objective)?	1. Are participants (organisations) recruited in a way that minimizes selection bias?	2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention	3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?	1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	2. Is the sample representative of the population understudy?	3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?	4. Is there an acceptable response rate (60% or above)?	Mixed methods 1. Is the mixed methods research design relevant to address the qualitative and quantitative research quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?	Mixed methods 2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?	Mixed methods 3. Is	appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?	Comments relevant to amber or red RAG rating
Frandsen & Kristensen 2002															Data analysis is unclear, some data is missing (screening data from Spain).

9.5 Appendix 5 PRISMA 2020 Checklist



PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Chapter 2 title
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	A separate abstract is not included as this formed part of a PhD.
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Chapter 2 Introduction, second sentence
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Chapter 2 At the end of the introduction after the aim
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Chapter 2 Under the headings 'Study selection process' and 'Inclusion and exclusion criteria', figure 1
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	'Appendix 1: Description of and rationale for databases used'
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	'Appendix 1: Description of and rationale for databases used' and 'Appendix 2: Search Terms, filters and limits'
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Chapter 2 'Study selection process'
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Chapter 2 'Methods' first line and 'Data extraction and synthesis'
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Chapter 2 'Data extraction and synthesis'.
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Chapter 2 'Appendix 3: Systematic Literature review data extraction tables'. Findings

Section and Topic	Item #	Checklist item	Location where item is reported
			section headings
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Chapter 2 'Data extraction and synthesis' second paragraph. 'Methods' first line
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	Appendix 3: Systematic Literature review data extraction tables
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Chapter 2 'Data extraction and synthesis'
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Chapter 2 'Data extraction and synthesis'
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Chapter 2 'Data extraction and synthesis'
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Chapter 2 'Data extraction and synthesis'
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	Chapter 2 'Data extraction and synthesis'
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Chapter 2 'Data extraction and synthesis'
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Chapter 2 'Data extraction and synthesis'
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Chapter 2 'Data extraction and synthesis'
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Chapter 2 'Figure 1 PRISMA 2009 Flow Diagram showing the number of studies identified at each stage of the process'
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Chapter 2 'Figure 1 PRISMA 2009 Flow Diagram showing the number of studies identified at each stage of the process' - Eligibility
Study characteristics	17	Cite each included study and present its characteristics.	'Appendix 3: Systematic Literature review data extraction tables'
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	'Appendix 4: Critical appraisal'
Results of	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an	'Appendix 3: Systematic Literature review

Section and Topic	Item #	Checklist item	Location where item is reported
individual studies		effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	data extraction tables'
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Chapter 2 'Limitations' first paragraph last sentence
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	'Appendix 3: Systematic Literature review data extraction tables'
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Chapter 2 'Summary' second paragraph
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	Chapter 2 'Limitations'
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	Chapter 2 'Limitations'
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Chapter 2 'Summary'
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Chapter 7
	23b	Discuss any limitations of the evidence included in the review.	Chapter 2 'Limitations'
	23c	Discuss any limitations of the review processes used.	Chapter 2 'Limitations'
	23d	Discuss implications of the results for practice, policy, and future research.	Chapter 7 7.10 Recommendations for practice and 7.11 Recommendations for further research
OTHER INFORMA	TION		
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	The review was not registered
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	A protocol was not prepared
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Not applicable
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Title page: The review was undertaken as part of a PhD which was funded by the University of Hertfordshire.
Competing interests	26	Declare any competing interests of review authors.	Chapter 2 'Method' first line: Data extraction and synthesis
			Data extraction and synthesis was

Section and Topic	Item #	Checklist item	Location where item is reported
			undertaken independently
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Chapter 2 and 'Appendix 3: Systematic Literature review data extraction tables'

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

9.6 Appendix 6: Information for participants

Participant information sheet

How will my taking part in this study be kept confidential?

If you take part any information which could identify you will be removed and will be treated confidentially and will not be accessed by anyone wider than the research team. No personal information will be stored on a computer. At the end of the study, all data will be stored by the researcher in a locked filing cabinet in the researcher's office for 10 years before it is destroyed.

For details on how to take part

The study has been reviewed by the University of Hertfordshire Ethics Committee for Studies Involving the use of Human Participants ECDA Protocol number aLMS/PG/UH/00099 (1)

please see the back of the leaflet.

If you would like to take part
please contact:
Jane McClinchy PhD student
University of Hertfordshire
College Lane Hatfield Herts AL10
9AB

Tel: 01707 285102 Email: j.1.mcclinchy@herts.ac.uk

Supervisor Dr Angela Dickinson, Senior Research Fellow, CRIPACC, University of Hertfordshire, College Lane, Hatfield, Herts, AL10 9AB. Tel: 01707 285993

Email: a.m.dickinson@herts.ac.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar, Sue Grant, at the University of Hertfordshire, College Lane, Hatfield, Herts, AL10 9AB.



Nutrition information for people with type 2 diabetes.

Participant information Version 2 7th Sept 2015



Introduction

This is an invitation to take part in a study which will be exploring nutrition information for people with type 2 diabetes.

What is the purpose of this study?

The purpose is to explore and map nutrition information accessed and used by people with type 2 diabetes, their partners/carers and health care professionals working with people with type 2 diabetes. This first phase of the study is aimed at those who are over 18 with type 2 diabetes or who are a carer for someone who has type 2 diabetes. (Vulnerable adults will be excluded).

What are the possible benefits of taking part?

Taking part will give you the opportunity to contribute to the research aiming to improve nutrition information for people with type 2 diabetes. If you do decide to take part you are free to stop or leave the study at any time. If during the study you do need access to information, you will be guided to ask your GP.



What will happen if I decide to take part?

You will be asked to keep a diary for 4 weeks about the sources, views and experiences of nutrition information in your day-to-day life.

To support you during the diary completion period you will be contacted by the researcher twice each week.

At the end of the 4 weeks the researcher will collect the diary. The researcher will also arrange a date and time for an in depth interview in your own home. The interview will last about one hour and will be recorded and transcribed word for word. This will be used to gain your reflections on your experiences relating to nutrition information as well as clarification of what you have recorded in the diary.



Participant consent form

UNIVERSITY OF HERTFORDSHIRE ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS
UH ECDA Protocol number | ALMS/PG/UH/00099

Supervisor			

PARTICIPANT CONSENT FORM

An exploration of nutrition information for people with type 2 diabetes

Name of Res	earcher: Jane McCli	nchy Ph	D Student	Please initial box
version 2 dat	m that I have read ted 7 th Sept 2015 f ask questions and	or the ab	ove study a	and have had the
withdraw at a	stand that my partici my time, without giv a collected from me	ing any r	eason. If I	
information ar accessed (as	stand that I will be nd that I will be as outlined on the atta at the interview can l	ked abou ched part	it nutrition i ticipant infon	nformation I have
	that any words I ma used, anonymously			
	peen informed that to lvised to contact my			
course of the	een told how informate study, and data it will be kept securoused.	provided	by me abou	ut myself) will be └──
	een told that I may ection with this study		ime in the fu	ture be contacted
8. I agree t	to take part in the ab	ove study.		
Name of Parti	cipant	Date	Sign	ature
Researcher		Date	Sign	ature
Consent Forms Place	on 1 receipt 2 7th Sout 201	5		

Consent Form Phase 1 version 2 7th Sept 2015

Interview topic guide

Nutrition Information Topic guide and personal deta	ils for interview revised 23.06.15
UNIVERSITY OF HERTFORDSHIRE ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ECDA Protocol number	Supervisor details

An exploration of nutrition information for people with type 2 diabetes:

People with type 2 diabetes or their carers semi-structured interview topic guide

Confirm consent to be audio recorded

Turn on recorder

Ice breaking questions

Before we look at the diary it would be very useful to find out a bit more about you 1.1 Tell me about your diabetes, how long have you had it?

- 1.2 Generally where do you find information about what to eat?
 - Are they a member of the local diabetes support group?
- 1.3 Are you working at the moment?
 - If not ask if they are retired
- 1.4 Do you live alone or are there other people in the household?
 - Who does the food shopping
 - Where and when is this done
 - Who does the cooking

2. Reflections on the diary entries

- 1.1 Can we spend some time now looking at the diary?
 - Give diary back to participant and ask them to take me through the diary.
 - Clarify anything unclear in the diary
 - Comment on any gaps in the diary
 - · Refer to any samples that were handed in with the diary
- 1.2 What did you think of the information collected?

Nutrition Information Topic guide and personal details for interview revised 23.06.15

UNIVERSITY OF HERTFORDSHIRE ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ECDA Protocol number	Supervisor details

- Go through diary entries
- Comment on any regular sources or unusual sources. eg I noticed that you used xx frequently,
- Based on sources that have been noticed following analysis of diary
- Ask about any potential sources that were not recorded in the diary-I noticed that you did not use information from ..list any potential sources HCPs, dietitians, pharmacists, structured education, internet, email newspapers, magazines, radio, television, food labels, recipes, friends or family.
- 1.3 Did you make any changes or take any action as a result of accessing any of the information?
 - Did you talk to whoever does the shopping
- 1.4 Were you prompted to look for information or did you just come across it?
 - Was there a particular trigger? e.g. active searching for information or just came across the information
 - What were you hoping to find out?
- 1.5 Is there any information that you recorded that you did not find useful?
 - If no response ask if there was any information that having accessed you did not use?
- 1.6 Were there instances when you were not able to find information that you needed?
- 2.0 Reflections on the diary process
- 2.1 Could you tell me how you found keeping the diary?
 - Did you find it easy or difficult to remember to keep the diary?
 - Did you have any strategies for reminding yourself?

Nutrition Information Topic guide and personal details for interview revised 23.06.15

UNIVERSITY OF HERTFORDSHIRE ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ECDA Protocol number	upervisor details
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- 2.2 By keeping the diary do you think it made you more aware of nutrition information than you would normally be?
 - Did you find you were searching for it more or less?
 - Did you find you settled down after a period of time?

3. Reflections on nutrition information in general

Now that we have reviewed the diary it would be useful to talk about your experiences of nutrition information since your diagnosis with type 2 diabetes.

- 3.1 Tell me about the nutrition information you have accessed across your diabetes journey.
 - When they were first diagnosed through to now eg
 - Do you recall the first person who gave you nutrition information
 - Did you take it on board
 - What advice have you had since then
 - o Or what ongoing support are you getting
 - have you ask for further advice from a dietitian?
 - are you getting an annual check up –what happens in that
- 3.2 Which of these sources had the greatest impact on you? Can you tell me why?
- 3.3 How did you come across these sources?
 - Was there a particular trigger? e.g. active searching for information or
 - if so what was it? –blood test, weight, BMI, visit to doctor?
 - just came across the information or a mix of these?
- 3.3 And any instances where the information you accessed was not useful?
- 3.4. Where do you mainly obtain your nutrition information from now?

Nutrition Information Topic guide and personal details for interview revised 23.06.15

UNIVERSITY OF HERTFORDSHIRE ETHICS COMMITTEE FOR	Supervisor details
STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ECDA Protocol number	

- Ask if they have had any nutrition information about diet and then availability from HCPs/diabetes education sessions, support groups, family, websites (mention Diabetes UK), media
- 3.4 In what ways do you use the information you find?
 - Have you been able to make use of the information?
 - Do you make any changes or take any action as a result of accessing any of the information?
 - What made you decide to use the information you found
- 3.5 Is there any information or sources of information that you are aware of that you have not accessed or found useful? Would you be able to tell me why?
- 3.6 Have there been instances in the past when you have not been able to find information that you needed?
- 3.7 Do you see anything about what to eat or anything ab out diet at the supermarket?
- 4. Suggestions for improvement in how nutrition information is made available
- 4.1 How would you have liked to have nutrition information made available to you

Thank you, clarify arrangements for further contact if needed

Nutrition Information Topic guide and personal details for interview revised 23.06.15 Supervisor details UNIVERSITY OF HERTFORDSHIRE ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ECDA Protocol number Personal details After the interview to help me with the project please could you answer the following questions about yourself? (to be completed by researcher) (note to researcher, some of the details may already be completed) (* use information already collected earlier) Name..... What is your date of birth? "What is the approximate length of time since you were diagnosed with type 2 diabetes? What is your postcode?..... Do you take any medication for your diabetes?.... If yes, what do you take Can you tell me if you have ever received nutrition information (advice leaflets) from: -On diagnosis Since Diagnosis Doctor Nurse Dietitian Diabetes educator Other □ please give details..... Are you a member of a diabetes support group?if yes, please give details...... What is the highest level of education you have completed? E.g. O Levels..... *Are you: Unemployed Employed Retired with private and state pension Retired with state pension What is your current occupation or if retired previous occupation? *Do you live alone or are there other people in your home? *Who does the cooking for your household? What is your ethnic group? Are there any foods you avoid because of religious or personal reasons? Date of Completion.....

Completed by.....

Email templates

8 emails
Email 1a Very nice to meet you this week/last week
Hope all is well with you and the diary!
Just to let you know that anything about food is useful! Eg conversations, recipes, websites newspapers/radio/food labels
Many thanks again
Kind regards
Jane
Email 1b Hope the diary is going OK!
Just to say that you don't need to record something everyday
Please do email or call on xxxxxxxxxx if you want to ask anything!
Many thanks for your help with the research
Kind regards
Jane
Email 2a I hope the diary keeping is going OK-remember you can take photos of any useful information!
Thank you again for your help with the research!
Kind regards
Jane
Email 2b
Hope the diary is going OK!
Please do email or call on xxxxxxxxxx if you want to ask anything!
Many thanks for your help with the research
Kind regards

Jane
Email 3a Please do save anything you come across, you can cut out and paste in the diary or just place in the plastic folder!
Many thanks for your help with the research
Kind regards
Jane
Email 3b Just over a week to go on the diary! Many thanks for your help with the research
Kind regards
Jane
Best wishes
Jane
Email 4a Not long now to completing the diary Many thanks for your help with the research
Kind regards
Jane
Email 4b Last day xxx
See you on the xxx for collection!
Many thanks
Kind regards
Jane

Follow up letter

Jane McClinchy PhD student

Contact details

Date:

Dear [Participant name]

Thank you very much for taking part in the project 'Nutrition Information for People with Type 2 Diabetes' in 2015/16. (Ethics number aLMS/PG/UH/00099(1)).

Your input to this study was invaluable and I have now collected and analysed all the interview/diary information collected from study participants. This is summarised in the attached leaflet/sheet along with a model I am developing that tries to explain my interpretation of the findings and how diabetes and managing what you eat is integrated into your lives.

It would be helpful to hear your opinion on the findings of this study – do you recognise your experiences in what I've written? This request is purely voluntary and I do understand if you are not able to respond.

If, however you do have ideas or thoughts, please make any notes below and/ or on the enclosed leaflet/sheet and send back to me using the business reply envelope enclosed, if possible by the middle of May. Alternatively my email address is: I would be delighted to hear from you.

Many thanks

Yours sincerely

Jane McClinchy

Copy to: Supervisor: Dr Angela Dickinson, contact details

My Comments are:

Integrating Diabetes: Nutrition information behaviour in people with type 2 diabetes

My interpretations

Twenty people with type 2 diabetes agreed to keep a diary for one month about information relating to nutrition and what to eat. After this each participant was interviewed about their diary entries and their access to and use of nutrition information. The diaries and the interviews were analysed for recurring ideas. These are summarised below and encapsulated in a model on the back of this leaflet. Both with participant diary entries and quotes to illustrate the points made.

Recurring ideas

- · Diabetes was integrated as part of people's lives
- Using information about food was an activity people did regularly
- People used a lot of different sources of information
- Food labels, recipes, their own weights and blood tests results were used by most people
- Food labels were confusing for many participants
- Recipes were adjusted to be suitable for someone with type 2.
 diabetes
- Weight and blood test results made people feel proud when they improved and frustrated when they did not.
- Information from the NHS was rationed, only being available to some and when it was available the advice conflicted between different practitioners and sources.
- Information about sugar and low carbohydrate diets were interesting to many participants
- Being able to learn from others living with diabetes about what to eat was the most useful

Writing in the diary was a useful exercise to make people aware of information

sounds like a satire.... Alot of these percentages when you add them up they come nowhere near 100%, they are like ten or twenty percent. So does that mean

a lot of the material in there

is rather like dark matter in

the universe?

It is important that one Should be in control of ones

Ludy, therefore, understo

of the dissus, thechurant

and diet is important.

I've drastically cut back on bread...I've cut back on... well all carbohydrates really I've cut back on. I've not cut them out, I have lost quite a lot of weight as well.

Starting this during is strange, mitting things down that Diabetes is around me everyday to emphosis awarenoss of it.

If you have ideas or thoughts on the findings of the study and would like to share these please make any notes on this leaflet and/or on the attached letter and send back to me by mid May using the business reply envelope. Alternatively my email address is:

Jane McClinchy PhD Student Supervisors: Angela Dickinson and Wendy Wills. April 2019

Follow up findings in newsletter format page 2

