



The  
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# **The Role of Online Support Groups in Empowering People with Type 2 Diabetes in the United Kingdom**

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The University of Sheffield

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*“I think what you're doing is ... a good thing to do this topic. I think you've hit on something that I don't know if you realise how important the forum is; but it is absolutely vital for people to turn it around diabetes. So, you have hit on something important! Do a good job of it. Get it out!”*

*Catherine – The Interview Study*

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## Abstract

### **Background and aim:**

Diabetes is one of the fastest-growing health threats of our times and an urgent public health issue. In 2015, there were approximately 415 million people diagnosed with diabetes globally, a figure estimated to increase to 642 million by 2040. In the UK, over four million people are living with diabetes and the number is estimated to increase to more than five million by 2025. Type 2 Diabetes (T2D) form the majority (i.e. ninety percent) of the diabetes population. People with T2D control more than 95% of their care and health providers have little control over the management of the illness. They make daily decisions related to the management of their illness within the context of their personal goals, priorities, family and work demands, and health issues. Therefore, health care systems around the world, including the UK, the US and the EU, have attempted to empower patients so that they can take care of themselves and make informed decisions. The World Health Organization, NHS and European Regional Office have included empowerment and patient-centred practice as key elements in their health 2020 report. Online support groups (OSGs) are reported to serve as a new supportive environment that can meet patients' needs to be empowered. OSGs have been found to provide emotional, informational and relational support for their participants. The aim of this study is to understand the role of OSGs in empowering people with Type 2 diabetes in the UK by undertaking an in-depth qualitative study.

**Methods:** A mixed qualitative methodology was employed in this study. To provide a better understanding of the research questions and to enhance the validity of the study, two research techniques were adopted as a process of triangulation: (1) thematic analysis of threads and posts of three UK-based OSGs; and (2) qualitative, in-depth, semi-structured interviews with OSG users that have T2D and live in the UK. A total of 76 threads and 738 posts from 250 unique members were purposively collected and analysed from all three OSGs. A total of 17 OSG users were interviewed. The data from both methods were analysed using Braun and Clarke's (2006) thematic analysis.

**Results:** Through thematic analysis, the study generated four key findings. First, OSGs have been used as a major source of informational, instrumental, appraisal and emotional support that help OSG members to overcome several barriers and challenges. Second, the use of OSGs introduced their members to treatment approaches that they had not known about prior to joining the community. These approaches, however, were not fully supported by many health care professionals (HCPs) which, as a result, created a tensional patient-doctor relationship. This was mainly because many OSG users preferred experience-based medicine over evidence-based medicine and/or various HCPs did not accept patients' involvement in care. Third, the study showed how various factors influenced the empowerment status for the participants of the study. In particular, it explained that information sources such as OSGs varied in their values, culture and norms which impacted on the empowerment status of their users. Finally, the study outlined the information journey of the participants of the study and identified their different roles in the OSGs.

**Contribution to knowledge:** The thesis has highlighted the importance of patient empowerment especially in managing long-term conditions such as T2D where individuals with the condition spend

a vast amount of time managing their condition by themselves and face challenges in doing so on a daily basis. In particular, the thesis shed the light on the enablers and barriers to implementing patient empowerment for people with T2D in the UK that use OSGs as a source of support. The thesis further identified possible recommendations for policy, practice and research that aim to enhance the implementation and understanding of patient empowerment for people with T2D in the UK.

**Keywords:** Patient Empowerment, Type 2 Diabetes, Online Health Support Groups, Peer Support, Medicine 2.0, Health 2.0.

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## List of Acronyms

CCGs	Clinical Commissioning Groups
CMHT	Community Mental Health Team
DCU	Diabetes.co.uk
DDP	Diabetes Prevention Programme
DSOU	Diabetes-support.org.uk
DUK	Diabetes.org.uk
GDM	Gestational diabetes mellitus
GP	General Practitioner
HbA1c	Hemoglobin A1c
HBM	Health Belief Model
HC	Health Care
HCE	Health Care Empowerment
HCPs	Health care Professionals
Hypo	Hypoglycaemic
LADA	Latent Autoimmune Diabetes in Adults
LC	Low Carbohydrates
LCHF	Low Carbohydrates High Fat
MODY	Maturity Onset Diabetes of the Young
NHS	National Health Services
NICE	The National Institute for Health and Care Excellence
OSGs	Online Support Groups
WHO	World Health Organization
SCT	Social Cognitive Theory
SEM	Social Ecological Model
SMBG	Self-Monitoring of Blood Glucose
T&Cs	Terms and Conditions
T2D	Type 2 Diabetes
TTM	The Transtheoretical Model
UGT	Uses and Gratifications Theory

# CHAPTER 1 : INTRODUCTION

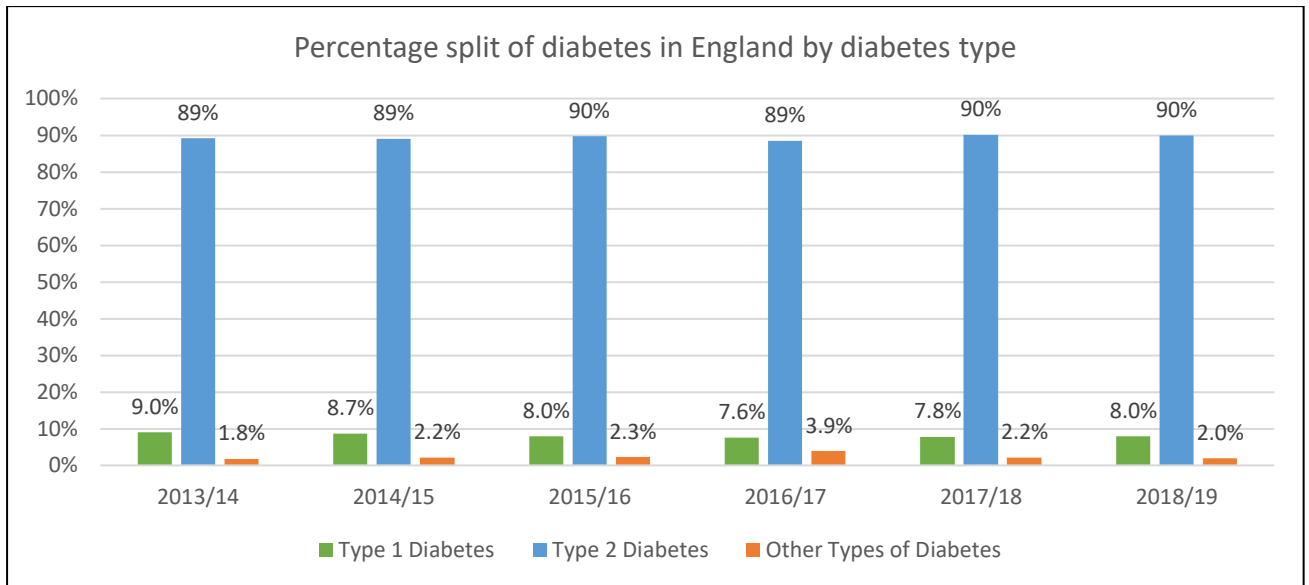
## 1.1 Introduction

Historically, health care professionals (HCPs) have taken most of the responsibility of health. During the course of the twenty-first century, however, this has changed with increasing emphasis on the responsibility of the individual too (Schneider-Kamp, 2020). The inclusion of individuals in care is seen as especially important for long term conditions such as diabetes. Type 2 diabetes (T2D) is a self-managed chronic disease in which patients control more than 95% of their care and health care providers have little control regarding management of the illness (Funnell & Anderson, 2000).

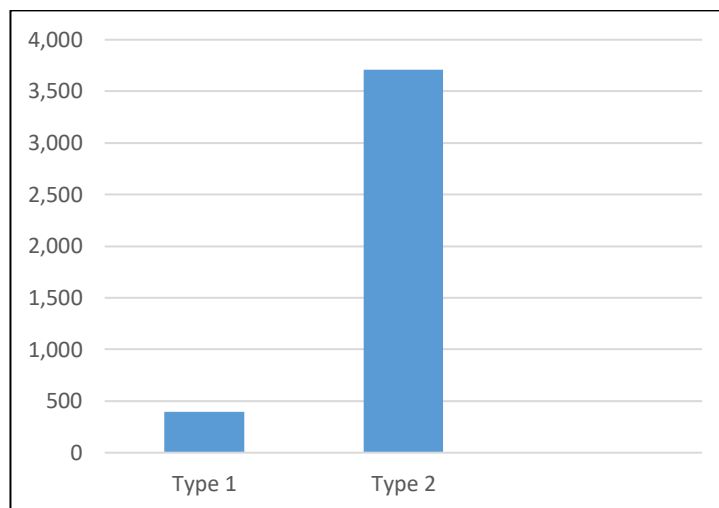
People with T2D face challenges and take decisions on a daily basis related to the management of their illness within the context of their personal goals, priorities, family and work demands and health issues. They have the right to set their own health goals and decide the best ways to achieve them, as well as carrying out these decisions and taking responsibility for the consequences. They spend around 8,760 hours a year managing their condition by themselves while they spend only three hours a year with their HCPs (Diabetes, 2019).

Therefore, it is especially important for diabetes care to change the focus of care from a doctor-centred to a more patient-centred approach. In order to successfully achieve this focus, patients need to be empowered to make informed decisions and manage their diabetes effectively. The social environment plays a significant role in facilitating empowerment for individuals (Gibson, 1991; Staples, 1990). Online support groups (OSGs) have been reported to serve as a new type of supportive environment that provides the support that patients need to be empowered (Oh & Lee, 2012). OSGs have been found to provide emotional, informational and relational support for their participants, resulting in the improvement of their sense of control, self-confidence, feeling of independence and social interaction skills (Barak et al., 2008). This research focuses on people with T2D, since they form the majority of people with diabetes (as shown in Figure 1.1), T2D cause more

deaths than Type 1 diabetes (T1D) (Figure 1.2) and, in contrast to people with T1D, they are usually diagnosed with the illness later in life (Diabetes UK, 2020), which might make them struggle in the transition phase and seek different types of support to people with T1D. Thus, it is important to empower people with T2D and understand the role of OSGs in empowering them.



**Figure 1.1 Percentage split of diabetes in England by diabetes type. Data Source: Adapted from the National Diabetes Audit (2019).**



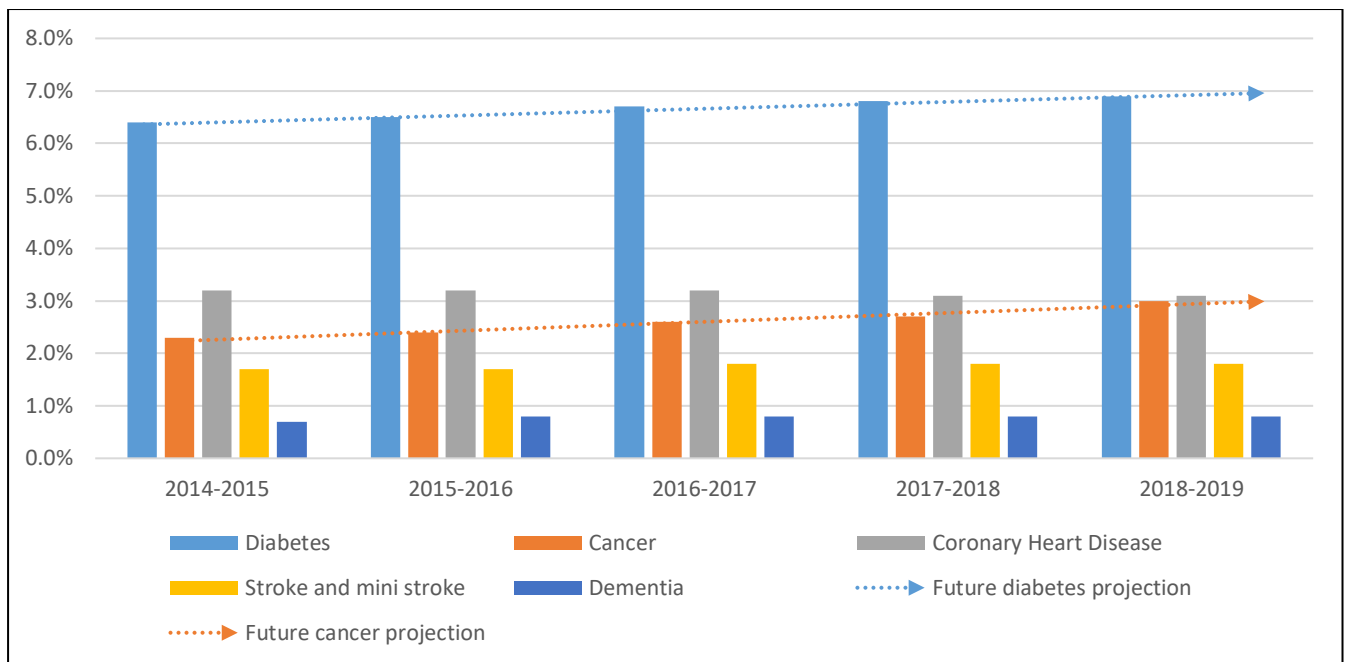
**Figure 1.2 Deaths caused directly by diabetes in England and Wales in 2019. Data Source: Adapted from the Office for National Statistics (2020)**

The current chapter continues in Section 1.2 with a brief exploration of the background context to the study, including diabetes, OSGs, patient empowerment and involvement in decision making. Section 1.3 will outline the aim and objectives of the research, Section 1.4 will discuss the importance of undertaking the study and Section 1.5 will outline the structure of the thesis. The chapter will be concluded by Section 1.6 which also introduces Chapter 2.

## **1.2 Research background**

### ***1.2.1 Overview of Diabetes***

Diabetes is a long-term condition that causes sugar (i.e. Glucose) levels in the blood to become very high (NHS, 2016a). The World Health Organization (WHO) defined diabetes as “a metabolic disorder of multiple aetiology characterised by chronic hyperglycemia with disturbances of carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action, or both” (WHO, 1999, p. 2). The causes of diabetes are multifactorial and include the effects of many genes in combination with environmental and lifestyle factors (Genetics Home Reference, 2017). Even though complex disorders usually cluster in families, they do not have a clear pattern of inheritance, which makes it difficult to predict an individual’s risk of inheriting or passing on any of these disorders. Complex disorders, such as heart disease, obesity, cancer and diabetes, are also hard to study and treat, since they are caused by many factors, all of which have not yet been identified. Diabetes has triple the prevalence rate of all types of cancer together (Figure 1.3), making it the fourth most common illness in England, after hypertension, obesity and depression (NHS Digital, 2020).



**Figure 1.3 Prevalence rates of different chronic illnesses in England. Data Source: Adapted from NHS Digital (2020)**

The WHO (1999) classified diabetes into four major types: Type 1, Type 2, Gestational diabetes and others. The main difference between Type 1 and 2 Diabetes is that the first is an autoimmune disease (i.e. that results from a mistaken attack by the body’s immune system), whereas the second is non-autoimmune (Palmer et al., 2005). However, both Type 1 and 2 are polygenic, which means that the cause of these forms of diabetes is related to multiple genes (National Institutes of Health, 2007). Further details about the different types of diabetes will be provided in Section 2.5.

Each person has two copies of most genes, one from each parent (NIH, 2007). Genes are responsible for providing instructions on making proteins within the cell. The protein might not function correctly when any of the genes are mutational, the DNA sequence of the gene being permanently altered. Of relevance here, the affected proteins are either unable to produce insulin or the produced insulin is unable to lower blood glucose levels. Therefore, diabetes is caused mainly by genetic mutations.

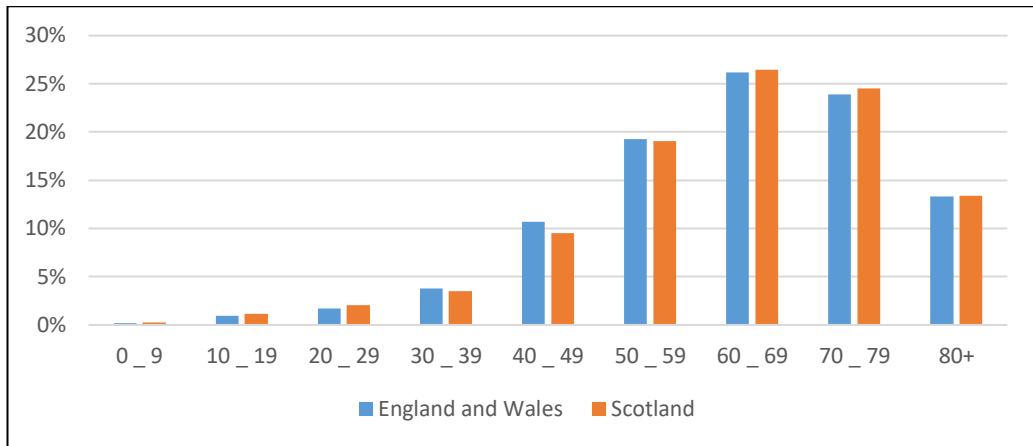
Diabetes is associated with other health conditions, or co-morbidities, such as blindness, heart disease, amputations and renal failure, and it doubles the risk of cardiovascular diseases (Abdulla et al., 2020; NHS England, 2014a). It also may be the cause of neuropathy, sexual dysfunction, complications in pregnancy and dementia (Diabetes UK, 2020). People with T2D face the risk of dying six years earlier than those without diabetes (Tang et al., 2020; The UK Department of Health, 2014). The majority of people with diabetes are diagnosed with T2D (as explained in Figure 1.1). In 2019, there were approximately 463 million people diagnosed with diabetes around the world (International Diabetes Federation, 2019) and the figure is estimated to increase to 642 million by 2040 (Cho, 2016). In the UK, around 4.9 million people have diabetes according to 2019 estimates: this figure includes both diagnosed cases, as shown in Table 1.1, in addition to undiagnosed cases as it is estimated that around 1 million cases have not yet been diagnosed (Diabetes UK, 2020).

**Table 1.1 Number of diagnosed people with all types of diabetes in the UK as of 2019**

<b>Country</b>	<b>Number of diagnosed people</b>
<b>England</b>	3,319,266
<b>Scotland</b>	301,523
<b>Wales</b>	198,883
<b>Northern Ireland</b>	99,833
<b>Total</b>	<b>3,919,505</b>

**Data Source: Diabetes UK (2020)**

Since the early symptoms are common (such as having a headache or being unusually hungry or thirsty), a soaring number of people remain undiagnosed (NHS, 2016a). Indeed, approximately one in two people with Type 2 are still not diagnosed around the world (Diabetes UK, 2020). The majority of people diagnosed with Type 1 and 2 diabetes are those in the age range of 50 and above (Figure 1.4).



**Figure 1.4 Distribution of Type 1 and 2 diabetes by age group in England and Wales and Scotland. Data Source: Diabetes UK (2020)**

Financially, diabetes accounts for approximately 12% of global health expense, equivalent to 760 billion US dollars (International Diabetes Federation, 2019). In the UK, it accounts for 10% of the NHS budget in England and Wales, equivalent to around 10 billion pounds, and nearly 80% of this budget is spent on treating diabetes complications (Whicher et al., 2020). Drugs prescribed for diabetes account for 12.5% of the total cost of prescribing in primary care in the UK (National Diabetes Audit, 2019).

Thompson and Lau (2015) illustrated that diabetes occurs when the body has either a total absence of insulin (Type 1), too little of it or cannot use it effectively (Type 2). The pancreas produces insulin to allow the body to use sugar from carbohydrates in food to generate or store energy for future use (Hess-Fischl, 2017). In order for the body's cells to produce energy, they need to absorb sugar (glucose). Without insulin, cells are unable to do so. Insulin additionally helps the body to store unused energy (Thompson & Lau, 2015). Without insulin, the sugar stays in the blood and causes the sugar level to be too high (Thompson, Romito & Lau, 2015). Public Health England (2018) reported that T2D is preventable and manageable by following healthy habits. They also stated that obesity, as well as other factors such as family history, age and ethnicity, influence the possibility of developing



diabetes. It has been reported that men have a significantly higher risk of developing diabetes than women in various populations (Choi et al., 2009; Emerging Risk Factors Collaboration, 2010; Lipscombe & Hux, 2007). Men, in fact, have a higher risk of developing diabetes at lower Body Mass Indices (BMI) across different age groups (Logue et al., 2011) because they are more insulin-resistant than women (Geer & Shen, 2009).

In 2016, the National Health Service (NHS) started a national initiative that aimed to reduce the number of people with T2D in England. The initiative (called the Diabetes Prevention Programme (DPP)) targets people who are at high risk of developing T2D with the intention to develop and deliver evidence-based behavioural interventions (Public Health England, 2016, 2018). The overall goals for the DPP are to reduce the number of people with T2D, to reduce other risks associated with diabetes, such as strokes, and to minimise health inequalities related to diabetes (Public Health England, 2016). It is therefore essential to increase knowledge about diabetes and to identify the best practices to manage the condition, as well as to prevent it.

### ***1.2.2 Online support groups (OSGs)***

Connecting to other patients who have similar health conditions has been associated with positive outcomes in the literature such as improving patients' knowledge and engagement with care providers (Lieberman et al., 2003; Merolli et al., 2013; Sturiale et al., 2020; White & Dorman, 2001). Patients have also been using multiple ways of communication (Oh & Lee, 2012). For example, face-to-face support groups started forming to connect patients with similar health conditions (Davidson et al., 2012). It is not clear when support groups exactly started to form. However, Davidson et al. (2012) dated the start of organised peer support groups back in the 18<sup>th</sup> century in a psychiatric hospital, Bicêtre Hospital, in Paris. They reported that the manager of the hospital employed some of the former patients because of their good attitude towards other patients. Recruited recovered patients were also chosen because they were found to be "averse from active cruelty" (p. 123), which was a

common management strategy in asylums at that time. This was a significant positive shift in hospitals, away from shackles and abuse, which started what is known as the “moral treatment” era. Alcoholics Anonymous (n.d.) is another example of a face-to-face support group which started in 1935 to help alcoholics to recover from their addiction. Support groups continued to grow over the years and have increased dramatically around the world in the last twenty years (Davidson et al., 2012).

According to the Oxford dictionary, a support group is “a group of people with common experiences or concerns who provide each other with encouragement, comfort, and advice” (Oxford English Dictionary, n.d., para. 1). These groups are based on the idea that people who share the same physical and mental conditions might understand each other more and be able to provide more effective emotional and informational support for one another (Barak et al., 2008). More generally, it is believed that life’s challenges can be faced better when having support from a group of people (Sundel & Glasser, 1985). Cline (1999) indicated that people living with life-threatening and chronic illnesses find mutual aid and self-help in support groups. Benefits from support groups include enhanced decision making, improved life quality and increased lifespan (Spiegel et al., 1989).

OSGs are an Internet-based version of physical support groups in which people with similar health issues can meet and exchange information and experiences and support each other online. Different forms of OSGs have been created since the 1980s (Potts, 2005). For instance, email lists and chat rooms were developed to enable people who shared the same health interests to discuss issues. More organised communities were established when web-forums were introduced to the Internet. Web-based forums were reported to be the most popular form of communication among patients due to their easy-to-use and friendly design (Meier, 2004). Patients used OSGs to break their isolation, obtain more information about their illnesses, express their feelings and receive support from others

(Gooden & Winefield, 2007). For the purpose of this research, the term OSG is specifically used to refer to online health forums. The benefits and limitations of OSGs will be discussed in detail in Section 2.6.1.

### ***1.2.3 Patient Empowerment***

This research investigates the effect of diabetes online support groups on patient empowerment. In common language, empowerment refers to “the process of becoming stronger and more confident, especially in controlling one's life and claiming one's rights” (Oxford English dictionary, n.d., para. 2). Diabetes patients, like other patients with long-term diseases, face a wide range of ongoing options regarding their treatments which requires them to have knowledge about the condition as well as the health care system (Chiauzzi et al., 2016). Patients whose access to health services are based on their income, social status, health insurance and education are particularly faced with these challenges (Agency for Health Care Research and Quality, 2014). To overcome such challenges, patient involvement in curing their conditions has attracted the attention of health care providers globally (Chiauzzi et al., 2016). The NHS in the UK has highlighted the importance of making patients more active and responsible for their own lives, stating that it is no longer considered as an option but a basic requirement (NHS, 2013). Subsequently, the NHS has launched a number of initiatives to empower people and communities (NHS, 2014). Similarly, in the U.S., the Institute of Medicine, the Patient-Centered Outcomes Research Institute and the Food and Drug Administration have also recognised the importance of shifting the focus on patients, through implementing a number of patient-centred programmes (Chiauzzi et al., 2016; Patient-Centered Outcomes Research Institute, 2013). The movement towards patient involvement in health care has been highlighted by studies which have found better health outcomes for people who had the required skills to manage their conditions which further resulted in reducing care costs (James, 2013; Patient-Centered Outcomes Research Institute, 2013).

Rappaport (1987) explained that empowerment is “a process, a mechanism by which people, organisations, and communities gain mastery over their affairs” (p. 122). For the purpose of this research, the term ‘empowerment’ will be used to refer to ‘patient empowerment’, which has been defined as “the discovery and development of one’s inherent capacity to be responsible for one’s own life” (Funnell et al., 1991, p. 38). Wentzer and Bygholm (2013) explained that “patients are thus empowered when they are in possession of the knowledge, skills, and self-awareness necessary to identify and attain their own goals” (p. 387). Although the concept of patient empowerment started to emerge in the 1990s (Funnell et al., 1991), it was first popularised by the Brazilian educator Paulo Freire (Anderson & Funnell, 2011) in the late 1950s (Wallerstein & Bernstein, 1988). He can be credited with developing the concept of empowerment (Simons-Morton & Crump, 1996; Wallerstein & Bernstein, 1988). According to Freire (2000), empowerment should be viewed as a social activity that includes group effort, not just an individual perspective, which leads to identifying the group’s problems and building strategies to overcome challenges and achieve their goals. Therefore, one of the basic aspects of the concept of empowerment is to make use of individual knowledge and competence to initiate change collectively (Wentzer & Bygholm, 2013).

Freire (2000) viewed empowerment as a process and, as a result of that process, as an outcome. As Anderson and Funnell (2010), illustrated:

“Empowerment is a process when the purpose of an educational intervention is to increase one’s ability to think critically and act autonomously. Empowerment is an outcome when an enhanced sense of self-efficacy occurs as a result of the process. However, while empowerment is an outcome, it is not a dichotomous variable, in that one is or is not empowered. Instead, empowerment is a continuous variable, more similar to a direction than a location” (p. 2).

Empowerment is a process whereby people take mastery over their lives and managing illnesses, as well as being an outcome in itself, i.e., a state of psychologically being enabled (Feste & Anderson, 1995; Roberts, 1999; Van Uden-Kraan et al., 2008). Anderson and Funnell (2010) stated that empowerment processes and outcomes are subjective and can vary between people.

The concept of patient empowerment seems particularly promising in the management of chronic illnesses (Anderson & Funnell, 2011; Chatzimarkakis, 2010; Kaldoudi & Makris, 2015), such as diabetes, which is a self-managed, long-term condition that is highly affected by a patient's decisions. A large number of these decisions are related to the patient's daily routines, such as physical activities and diet habits. Anderson and Funnell (2005) explained that successful collaboration between HCPs and patients helps to achieve an effective self-management plan for diabetes that combines the knowledge and expertise of HCPs and the preferences, concerns and resources of patients. As Cochran (1987) illustrated, people understand their own needs better than anyone else; therefore, they should have the right and power to define and act upon these needs. The WHO (1986) confirmed that complete health potential cannot be achieved unless people are able to control the issues that determine their health. McClelland (1975) explained that, in order for people to be in power, they need to be informed and willing to collaborate with others to drive the change. In this study, online support groups will be investigated as a source of information to empower diabetes patients.

#### ***1.2.4 Patient involvement in decision making***

This research studies the role of OSGs in patient empowerment. An important aspect of being empowered is patients' involvement when making decisions related to their health. Decisions are taken from the early stages of the illness, even from when a patient starts having a symptom and

suspects that they have developed an illness. Whether involving taking a pain-killer, visiting a doctor or taking a diagnostic test, patients' decisions are critical to their health.

There is growing interest in making patients more active when it comes to making decisions related to their health (Jolles et al., 2019; NHS, 2013). This is known as 'shared decision' making. Shared decision making refers to "a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences" (Coulter & Collins, 2011, p. 7). These authors illustrated how decisions might be related to: undertaking a screening or diagnostic test; undertaking a procedure; taking a medication (or not); or making a change in lifestyle. Involving patients in decision-making is a controversial issue. On the one hand, there is the opinion that patients should take some responsibility to participate in decisions related to their health, while, on the other hand, there is the view that patients should not be encouraged to participate in decision-making since they do not have the required knowledge and experience (Degner & Sloan, 1992; Foot et al., 2014), or may not wish to take responsibility for decision-making. In between these two opposing sides, others have suggested the need for patients to acquire the appropriate skills and knowledge before participating in health decisions (Fumagalli et al., 2015; Kata, 2010). The level of involvement of patients in the decision-making process depends on the illness, age and social class (McKinstry, 2000). According to the UK Department of Health (2007), 76% of patients reported that they wanted to be involved when making decisions related to their health. It is critical, therefore, for HCPs to understand the preferences of patients, independently of whether and how patients want to participate in making the decisions.

The NHS supports the shared decision-making culture and wants it to become the norm in the UK health system (Coulter & Collins, 2011). It is important for patients to be confident about their treatment plans so that they follow them precisely. Patients who are actively involved when doctors

make decisions regarding their health have shown better outcomes than those who are not involved (Beedholm & Frederiksen, 2019; Coulter & Collins, 2011). In addition, shared decision making allows commissioners to reduce unwarranted variations in doctors' performance so patients "receive the care they need and no less, and the care they want and no more" (Mulley, Trimble & Elwyn, 2012, p. 2). However, patient involvement in care is considered as one aspect /element of empowerment which is seen as a collection of various aspects/ elements (Johnson, 2011). Therefore, the Health Care Empowerment Model was employed in the present study to understand empowerment and its factors/ elements (explained in Section 2.3.4.4).

### **1.3 Aim and objectives of the research**

The overall aim of this study is to investigate the influence of OSGs on patient empowerment for people with T2D. More specifically, the research objectives are:

- To identify the informational needs and informational behaviours of people with T2D through their use of OSGs.
- To develop a better understanding of how the use of OSGs by people with T2D can support patient empowerment (specifically in relation to patient engagement, their being informed, collaborative, committed and able to cope with uncertainty).<sup>1</sup>
- To investigate how different contextual and interpersonal factors, as well as personal resources,<sup>1</sup> affect patient empowerment among people with T2D who use OSGs.
- To describe how people with T2D utilise the information they receive on OSGs and how this influences their health behaviours.

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<sup>1</sup> These concepts are part of the Health Care Empowerment Model which will be explained in Chapter 2, Section 2.3.4.4.

## **1.4 Importance of the research**

This study is important for four main reasons. First, as discussed in Section 1.2.1, diabetes is a major issue for health care systems around the world and has critical implications for both individual patients and health organisations. Thus, it is important to develop knowledge of how to prevent, control and manage diabetes effectively. It is also critical for health professionals, patients and researchers to be informed about best treatment practices. The condition is usually self-managed and hence requires a high degree of patient involvement in the health care. Being knowledgeable about diabetes can prevent and/or control the condition effectively and this study investigates the role of information in changing diabetes patients' behaviour.

Second, the increased availability of information is making patients more active in consultations and their health decisions, and is thereby moving them away from the traditional medical model (Wilson, Kendall & Brooks, 2007), where decision-making lies in the hands of practitioners. Health organisations from around the world, including the NHS, have shown interest in empowering patients and involving them more in decision-making. The NHS (2013) stated that shared decision making is no longer an option for patient care, but is an essential requirement. A number of programmes have been created, including the 'National Shared Decision Making' and 'Ask 3 Questions', that embed the culture of patient empowerment in the NHS system and achieve the involvement of 80% of patients in their health decisions (NHS, 2013). The NHS has also reported that the Internet is a key source in the move to empower patients and enable them to make informed choices (Henwood et al., 2003). Thus, this study examined the effectiveness of OSGs as an information source for patients with diabetes, and especially in relation to patient empowerment.

Third, and as will be demonstrated in Chapter 2, to the best of the researcher's knowledge, there has not been any in-depth study about the role of OSGs on patient empowerment for people with T2D in



the UK. There is a clear lack of investigation of the effect of OSGs on patients' personal health decisions. Previous studies have identified this need and recommended research on this (Himmelboim & Han, 2014; Househ et al., 2014; Huber et al., 2017).

Fourth, this investigation is important especially for patients with chronic illnesses whose disease is a life journey and who need to make critical decisions related to their health on a daily basis. These decisions might be related to their medicine, treatment options, lifestyle and relationship with doctors, all of which have a direct impact on their well-being. Whether OSGs have a major or minor impact on the management of the condition for patients, the factors that change patients' initial plans and the results of these health-related changes on patients' health remain unknown and are in need of being identified. Answering these questions will help understand how patients receive information from OSGs and how they process and utilise this information; this, in turn, may have a critical impact on patient health. Consequently, there is a need to understand the role and effect of OSGs on patient empowerment. This study added to the existing body of knowledge by filling this gap (see Section 7.3).

## **1.5 Thesis structure**

This section describes the content of the thesis which is organised into seven chapters as follows:

**Chapter 1: Introduction.** This chapter discusses the context of the research. In particular, it introduces the concepts of the study such as patient empowerment and OSGs. The first chapter also discusses the aim, objective and significance of the study.

**Chapter 2: Literature review.** This chapter provides an extensive examination of the extant literature in relation to health information behaviour, diabetes, digital information resources and

patient empowerment. The chapter concludes by providing a synthesis of the literature, identifying gaps found in the literature and outlining the research questions.

**Chapter 3: Methodology.** This chapter outlines the research philosophy and then discusses the research methodology employed in the present study. The chapter then provides an overview of the data collection and analysis techniques before reflecting on the ethical considerations encountered throughout the research and quality criteria used to ensure the quality of the study.

**Chapter 4: The Health Online Support Groups Posts Study.** This chapter describes the first phase/ qualitative study in the thesis. This study examined purposively selected threads and posts from three UK-based diabetes OSGs. The chapter presents the results of the thematic analysis of the data and then discusses the findings in relation to previous studies.

**Chapter 5: The Interview Study.** This chapter reports on a qualitative interview study conducted as the second phase/ study of this mixed qualitative methods research. In this chapter, the experiences of seventeen individuals who used OSGs to control and manage their T2D are presented. The chapter then discusses the findings in relation to the extant literature.

**Chapter 6: Discussion.** This chapter aims to bring together the findings of the previous two studies. In particular, it consolidates and interprets the findings to understand the informational behaviour of people with T2D using OSGs, their online behaviour and the impact of that on their empowerment status. The chapter discusses the findings in light of the literature and related theories/models.

**Chapter 7: Conclusions and Implications.** This chapter summarises the findings of this research by re-visiting the research questions and explaining how they have been answered. The chapter then

explains the contribution of the thesis to the existing body of knowledge and outlines recommendations for practice and policy. Finally, the chapter concludes with a discussion of the limitation of the study and providing suggestions/ directions for future research.

## **1.6 Conclusion**

This chapter has introduced the proposed research by setting out the overall background to the research area, and identifying the aim, objectives and importance of the research. The chapter concluded with an outline of the structure of the thesis. In the next chapter, a comprehensive literature review of previous related studies will be discussed to identify the research gap and research questions that will be addressed in this study.

## **CHAPTER 2 : LITERATURE REVIEW**

### **2.1 Introduction**

Chapter one highlighted the general background and objectives of undertaking this thesis. The aim of the Literature Review Chapter is to provide a critical review of the studies related to the usage of OSGs as a resource for patient empowerment. Specifically, the chapter reviews research relevant to health information behaviour (Section 2.3), health literacy (Section 2.4), diabetes (Section 2.5), digital information resources (Section 2.6) and patient empowerment (Section 2.7). The Chapter starts with explaining the search strategy used to identify related literature (Sections 2.2) and concludes with synthesising the literature (Sections 2.8), identifying the gaps (Section 2.9) and outlining the research questions (Section 2.10).

### **2.2 Literature Search Strategy**

In order to undertake a comprehensive review, multiple databases were searched to cover the themes described in Section 2.1, including Google Scholar, the ACM digital library, Web of Science (formerly Web of Knowledge), IEEE explorer, Scopus and Medline. These databases cover most of the main areas related to this study such as information science, health informatics and computing. A combination of search terms was used including ‘online’, ‘Internet’, ‘virtual’, ‘web 2’, ‘forum\*’, ‘communit\*’, ‘support group\*’, ‘diabetes’, ‘health’, ‘patient\*’, ‘empower\*’, ‘decision\*’, ‘decision-making’. Only papers published in English were included. Reference lists of key papers were also searched.

## 2.3 Health Information Behaviour

### 2.3.1 Information

*Informatio* is the Latin root of the word information and has Greek origins (Capurro & Hjørland, 2003). According to these authors, the word has been used since before the Christian period. It is reported that the words *informatio* and *informo* were used since Vergil (70-19 BC) (Thesaurus linguae Latinae, 1990). *Informatio* has two main related meanings; the first one is: “the action of giving a form to something material” and the second is: “the act of communicating knowledge to another person” (Capurro, 2009, p. 128).

The word *information* entered the English language in the 14<sup>th</sup> century as an item of new knowledge (Peters, 1988); however, even though it has been in the English language for hundreds of years, there has not been a consensus on its meaning (Case, 2012). Schrader (1983) argued that the term information has a multiplicity of vague, contradictory and occasionally bizarre notations. Part of the problem, as Case (2012) explained, is due to the fact that information has been used to denote many overlapping concepts from multiple disciplines. Wilson (2003) confirmed that information is not a simple phenomenon that can be simply identified among various professions. Therefore, these various meanings and associations between ‘information’ and other concepts made it difficult to have a universal definition for the term. Many efforts have been made to define information from different points of view. Some of these definitions are discussed below, based on the numerous definitions proposed by many scholars. For instance, Wersig and Neveling (1975) identified 17 different definitions. Schement (1993) reported 22 definitions of the term information. After two decades of struggling to find a proper definition, Bateson (1972) defined the term information as “any difference which makes a difference in some later event” (p. 386). Based on this definition, Case (2012) formulated his own designation of information which is “whatever appears significant to a human

being, whether originating from an external environment or a (psychologically) internal world” (p. 46).

Buckland (1991) identified three meanings of the word information based on its uses. The first use is “information-as-process”, which refers to the act of telling and knowing. Secondly, it is used to refer to “information-as-knowledge”, which indicates what is perceived in the previous use. Lastly, information is used as a “thing” to refer to informative objects such as documents and data.

However, every definition has its own assumptions and requirements that make it applicable to a specific domain. Case (2012) identified five difficult problems in defining information, which leads to different definitions mostly because of different views on these issues. Therefore, he concluded that when starting researching information phenomena, information definition is not required.

People with diabetes explore a wide range of information including medical, disease-specific information, as well as information on exercise, diet and stress management (Jean, 2017; Jean et al., 2019; Longo et al., 2010). Thus, it is important to adopt a broad view of the information phenomena in this research. For the benefit of the research, Bateson's (1972) definition of information, “any difference which makes a difference”, was adopted in this study since it offers a broad view of the term. However, the researcher reviewed studies on health and diabetes-related information behaviour in order to create a full picture from different beliefs.

### **2.3.2 Information needs**

Similar to ‘information’, the concept ‘information need’ is arguable too. Krikelas (1983) explained that terms derived from information have an equivalent amount of definitions as for information itself. Dervin and Nilan (1986) defined information need as the force to understand a present situation. It happens when a person expresses a gap in his or her knowledge and is willing to resolve

it (Belkin & Vickery, 1985). Information needs come from the realisation of requiring information that can help individuals with a task or the realisation that they have a gap in knowledge that needs to be fulfilled (Nicholas & Herman, 2010). Therefore, Kuhlthau (1993) explained that fulfilling an information need is not a static procedure because it might cause another information need. Wilson (1981) explained that information need is a result of other significant needs such as physiological, affective and cognitive needs.

In the case of people with diabetes, an obvious basic need is coming from their concerns about their health status. When diagnosed, patients with diabetes were reported to be mostly concerned about injections, lifestyle impact, complications, diet restrictions and uncertain future (Beeney et al., 1996; Seehusen et al., 2019). These concerns and psychological requirements cause patients to have need of information, which must not to be neglected (Beeney et al., 1996; Seehusen et al., 2019). After their formal diagnosis, patients with T2D are reported to leave their general practitioners with unfulfilled information needs (Peel et al., 2004; Zhang, 2017). As the chronic disease changes over time, patients become unsure and confused and face increased seeking of information and empowerment (Kralik & Australia, 2003; Zhang, 2017). They study their actions and learn about new medications and care options (Jean, 2017). Kuske et al. (2017) explained that people with diabetes have information needs mainly regarding diet, medications, exercise and diabetes complications. Consequently, it is especially essential to provide information and emotional support for diabetes patients to aid informed decision making (Zhang, 2017). Kuske et al. (2017) also reported that HCPs, diabetes groups, friends/ family and other individuals with the condition, books and the Internet were the most used sources of information to fulfil the informational needs of people with diabetes. Therefore, OSGs provide platforms that enable their users to seek information support from other peers in the groups to fulfil their information needs.

### **2.3.3 Information seeking**

To fulfil a need and achieve a goal, information seeking "is the purposive seeking for information" (Wilson, 2000, p. 2). Case (2012) explained that many scholars have not discussed the term 'information seeking' as much as 'information needs' because the term 'seeking' seems to be obvious. He explained that seeking information is normally done as a response to a need for information. Marchionini (1997) defined information seeking as "a process in which humans purposely engage in order to change their state of knowledge learning and problem solving" (p. 5). Through it, people understand and build their perspectives on different issues (Dervin, 1983) and it is affected by the particular circumstance in which it happened (Wilson & Walsh, 1996; Wilson, 1981).

Numerous scholars have developed models that represent the information seeking process, including various models that are specific to health (e.g. Griffin, Dunwoody, & Neuwirth, 1999; Johnson, 1997) and others specific to health information seeking on the Internet (e.g. Yun & Park, 2010; Marton, 2010). Kuhlthau (1991), for example, represented the information seeking process in six linear stages: "initiation, selection, exploration, formulation, collection and presentation" (p. 7). The model considers cognitive and affective aspects that a user might face when experiencing information seeking. Ellis, Cox and Hall (1993) identified eight essential features of information seeking activities. In general, initiation and formulation, exploration and extraction and finishing are three broad information seeking stages that were seen the most in previous information-seeking models (Lopatovska et al., 2016).

A more recent set of data collection and user-modelling studies have appeared to understand Internet users' information seeking behaviour (Berget et al., 2020; Choo et al., 2013; Havelka et al., 2020). These new Internet-based models are primarily based on detectable patterns of Internet users' activity or content. Turnbull (2005) illustrated that it is expected to generalise a set of habits from



these patterns that can either form a new basis for information-seeking models or be integrated with or into existing ones. He explained that habits and routines are dominant in terms of information seeking behaviour and it is useful to explore the effectiveness of existing information seeking models to describe the seeking behaviour of Internet users. Knowledge Discovery in Databases (KDD) and data mining techniques are increasingly employed to analyse large-scale datasets of Internet use activity. For example, Li and de Rijke (2019) collected Web browsing sessions from many users and analysed their browsing patterns to understand how Internet users seek information. Other scholars (e.g. Aribarg and Schwartz (2020) have analysed logs of a Web site server to understand how users navigate when surfing the website. Other researchers (e.g. Choo et al. (2000)) developed models to understand how Internet users seek information on the Web.

The concepts of information, information needs and information seeking were outlined in this section and the next section will discuss different information behaviour models that are used to explain different behaviours.

#### ***2.3.4 Theories and models relevant to the research***

Glanz, Rimer and Viswanath (2008) defined theory as “a set of interrelated concepts, definitions, and propositions that present a systematic view of events or situations by specifying relations among variables, in order to explain and predict the events or situations” (p. 26). In general, each theory contains primary elements, which are: concepts, constructs, and variables (Glanz et al., 2008). For instance, *Self-efficacy* and *outcome expectancies* are the two main constructs of the Social Cognitive Theory, which aims to understand education behaviour (Schwarzer & Luszczynska, 2005). The theory has been applied to a variety of domains including school achievement, physical and mental health, emotional disorder and socio-political change.

Because human behaviours are too complicated to be explained by a single theory, models have been developed to help understanding. Models are drawn “on a number of theories to help understand a specific problem in a particular setting or context” (Glanz et al., 2008, p. 29). They are usually informed by multiple theories and empirical findings (Earp & Ennett, 1991). The Health Belief Model and Wilson's (1999) information behaviour model are two typical examples of models. The two terms, theory and model, are interchangeably used to refer to a visual representation of the element of a theory (Conner & Norman, 2005; Earp & Ennett, 1991). Therefore, in this study, the two terms were used to refer to the representation of elements of theories or models that were developed to help understand and predict human behaviour.

In order to understand how people with T2D use OSGs as a tool of empowerment, a number of related models were studied and the health belief model was chosen to be the most appropriate model to the context of the study. Glanz et al.'s review of 116 theory-based articles in two main health education journals between 1986 and 1988 found that The Theory of Reasoned Action, social learning theory and the health belief model (HBM) were the most frequently mentioned theories (Glanz, Lewis, & Rimer, 1990). Another review looked at 526 articles from 24 health education and medicine journals between 1992 and 1994 reported the eight most common theories, including the HBM and Social Cognitive Theory (SCT) (Glanz, Lewis, & Rimer, 1996). Between 1999 to 2000, the SCT and the Transtheoretical Model (TTM) were the most used theories besides the HBM (Glanz, Rimer, & Lewis, 2002). Lastly, between 2000 and 2005, the HBM, SCT and TTM appeared to be the leading theories (Glanz et al., 2008). Considering the above, a general overview of the most-used theories as well as the theories related to the findings of the present study are discussed below.

#### **2.3.4.1 The Transtheoretical Model**

The Transtheoretical Model (TTM) is a dominant model in psychology that was developed in an attempt to integrate more than 300 psychotherapy theories (Prochaska, Redding, & Evers, 2008). Prochaska and DiClemente (1982) developed the TTM or, as it is sometimes called, the stages of change model (SoCs), in the 1980s to understand smokers behavioural change: it has been widely used afterwards in understanding behavioural change in smoking cessation (Taylor et al., 2006), as well as other health domains such as weight control, quitting cocaine and sunscreen use (Prochaska et al., 1994).

According to the model, people undergo a sequence of phases when altering their behaviour (Pitts & Phillips, 1998). The TTM offers an understanding of the relationship between these phases (Redding et al., 2000). Prochaska, Redding and Evers (2008) described the five main stages of change in the model as follows:

- *Pre-contemplation:* No plans have been thought about to perform any activity during the following six months (for example, a person accepts his obesity and does not see a need to start and maintain an exercise programme).
- *Contemplation:* A plan has been intended to be performed within the following six months (e.g. the person is seriously thinking about starting an exercise programme).
- *Preparation:* There is an intention to take action within the next month and has taken few behavioural steps (e.g. the person has started looking for gyms or has bought a sports outfit).
- *Action:* Individual's behaviour has been altered for fewer than six months (e.g., a period from nought to six months in which the person is actually exercising).
- *Maintenance:* Changed overt behaviour for more than six months (e.g., the period that follows the previous one).

In other forms of the model, *termination* is the last stage, in which the adapted behaviour is considered as fully settled (Taylor et al., 2006). Individuals in this stage have zero temptation and 100% self-efficacy. Prochaska, Redding, and Evers (2008) reported that after 12 months of continuous abstinence, 43% of people who had smoked returned to smoking, while the percentage dropped to only 7% after five years of continuous abstinence. In *situational temptations to relapse*, people tend to go back to their old habits, which take place either in the *action* or *maintenance* stages. The advance made by individuals does not appear linear, but seen as ‘a spiral staircase’ upon which subjects might on occasions rise and fall (Taylor et al., 2006). People could go through the stages several times before either adapting (or not) the desired behaviour (e.g. being free of an addiction).

Pitts and Phillips (1998) argued that the TTM is temporal and describes the process of change rather than only identifying the precursors to that behavioural change. They clarified that the decision-making component of the TTM model was driven from Janis and Mann's (1977) conflict model that was highly focused on identifying and majoring the benefits and costs (pros and cons) associated with a behavioural change. Prochaska et al. (1994) applied the model to 12 different health issues and found that the disadvantages of changing a behaviour were higher than the pros in the pre-contemplation stage.

Although the model has been widely applied to different problematic health behaviours, such as addictions, under which it was developed, it was felt not to be appropriate to be fully applied for the domain of this study. The model focuses on measuring different behavioural change stages, which is not the aim of this study. However, the study used the model to interpret some of the findings as Section 2.3.5 explains.

#### **2.3.4.2 Social Cognitive Theory**

The Social Cognitive Theory (SCT) was published by Bandura (1986) and it was first known as the Social Learning Theory (SLT), as it was based on theories of human learning in the social context (Bandura, 1977; McAlister et al., 2008). To advance the understanding of human capacities, the SCT adapted theories and concepts from cognitive psychology, sociology, political science and humanistic psychology (Bandura, 1997, 1999). The theory has been widely used to prevent, promote and modify many health behaviours (Redding et al., 2000).

The SCT includes a method of health behaviour alteration that covers elements not only related to persons but also related to the surrounding environment (Redding et al., 2000). Its unique feature, as LaMorte (2016a) pointed out, is the emphasis on social influence and external and internal social reinforcement. It positions self-efficacy and action-outcome expectancies as central determinants of behaviour. Redding et al. (2000) explained that the theory suggests that a behaviour can be understood in terms of three key concepts which operate as determinants of each other. These three factors, whose continuous dynamic interaction produces human behaviour, are: personal, environmental and behavioural factors.

The theory encompasses two primary constructs. The first is *self-efficacy*, which refers to people's beliefs in their capabilities to complete a specific task to achieve a wanted result. The second construct is *outcome expectancies*, associated to people's beliefs on what might occur because of their actions (Schwarzer & Luszczynska, 2005). Along with these two constructs, the SCT also contains goals and perceived impediments and opportunity structure. According to this theory, behaviour correlates to individual education history, their expectation in a specific setting, as well as their inside and outside abilities. Thereby, behaviour is influenced by going through new

experiences, such as a new education experience, direction in adapting new settings and support for the growth of abilities (McAlister et al., 2008).

LaMorte (2016a) argued that the SCT assumes that any change in the environment will automatically change the person, which is not always true. For many individuals, behaviours are consistent regardless of changes in the environment. The theory also was criticised for its unorganised structure, which makes it difficult to know how much each component of the theory influence the behaviour the most (Flamand, 2012; LaMorte, 2016). For this study, the SCT was felt not to be the best theory to adapt, because it highly emphasises that a behaviour is learned from the environment through observational learning, which is not relevant in the context of the study. This is because it focuses on the environment as a key factor and ignores an individual's emotions and perceived susceptibility to illnesses, which might motivate people with diabetes to perform a behaviour more than the environment itself.

Although the study did not adopt the SCT as it was seen as inappropriate for the current study, it was intended to use it to understand some of the findings, as Section 2.3.5 explains.

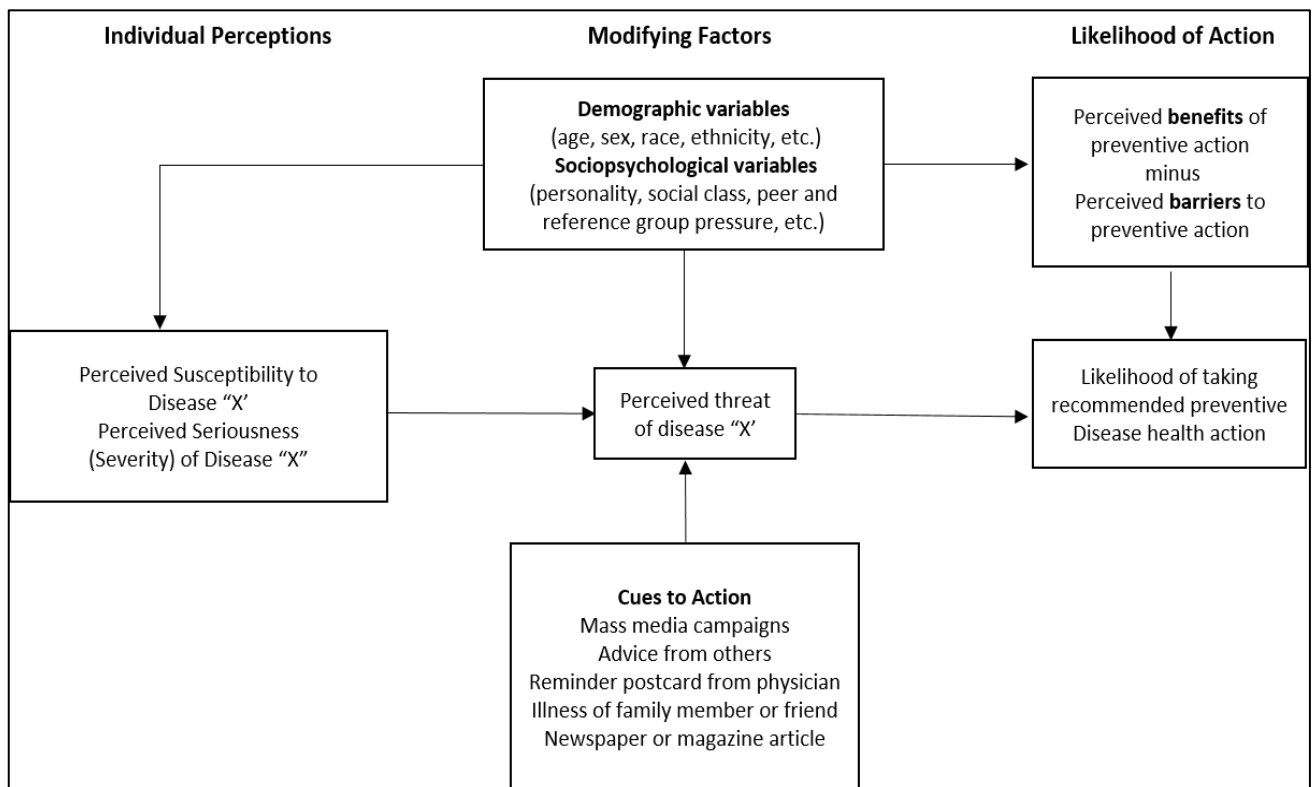
#### ***2.3.4.3 Health Belief Model***

The health belief model (HBM) was developed in the 1950s by Drs. Hochbaum, Kegeles, Leuenthal and Rosenstock at the U.S. Public Health Service to predict and explain behaviours related to tuberculosis screening (Hochbaum, 1958; Rosenstock, 1974). It then became widely used in studies concentrating on health behaviour (Ahmed et al., 2019; Hayden, 2013). The HBM was first designed to understand individuals who do not take a successful part in programmes centred on addressing tuberculosis (Champion & Skinner, 2008; Hochbaum, 1958; Rosenstock, 1974). Later, it grew to provide an understanding of individuals' behaviour after being diagnosed with a medical complication (Becker, 1974). It contains a number of concepts that predict why people want to take

actions that help them in preventing, diagnosing or controlling an illness (Glanz et al., 2008). To predict people's action, the model focuses on individuals' attitudes and beliefs (Rodriguez, 2014). The model assumes the existence of a strong relationship between behaviour, socialisation and beliefs.

The HBM's main concepts were obtained from well-established psychological and behavioural theories, whose models assume that behaviour depends basically on two main variables: "(1) the value placed by an individual on a particular goal; and (2) the individual's estimate of the likelihood that a given action will achieve that goal" (Janz & Becker, 1984, p. 2). The authors explained that when these two variables were conceptualised within the context of health behaviour, the equivalents were: (1) the individual's desire to avoid a disease (or to recover from a disease if ill); and (2) the belief that the disease could be prevented (or ameliorated) by taking a particular health action. The health belief model is based on the assumption that human behaviours are directed by expectations which result in satisfying these expectations. Additionally, it assumes that the health beliefs of individuals are changeable and influenced by group values. Figure 2.1 outlines the health belief model. According to Pitts and Phillips (1998), the model indicates that, for a person to take an action to prevent a disease, he or she must:

- Feel susceptible to the illness (perceived susceptibility).
- Feel that the condition might have serious consequences on his or her health status (perceived severity).
- Feel that his or her action might have an impact in preventing the illness or limiting its severity (perceived benefits).
- The perceived benefits of the preventive action should not be outweighed by any barriers (such as pain or costs) in order for the health action to occur.
- That cues of action might motivate the person to the proposed action.



**Figure 2.1 Health Belief Model. Data Source: Adapted from Becker and Maiman (1975)**

As Figure 2.1 shows, the model consists of four main dimensions: *perceived susceptibility*, *perceived severity*, *perceived benefits* and *perceived barriers*. Janz and Becker (1984) illustrated that the first perception refers to the individual’s subjective perception of the risk of developing an illness. People vary in their feelings and responses to a condition. The model argues that people will not act on preventing a negative health threat unless they feel and believe that they are susceptible to that illness (Rosenstock, 1966). For instance, a woman is less likely to get a mammogram if she believes that she is not likely to develop breast cancer (Hyman et al., 1994). *Perceived severity* refers to people’s evaluation of perspective consequences of a negative health condition. Evaluating an illness and its consequences and treating it with seriousness varies between people. The model estimates that the stronger an individuals’ perception of the severity of an illness the more likely they will be to take an action to prevent it (Carpenter, 2010; Rosenstock, 1966). If individuals believe that a condition will



not have a large impact on their life, they are less likely to act on it (Carpenter, 2010). The third dimension, *perceived benefits*, indicates that the action must be seen as feasible and effective in the individual's point of view in order to take it. If the individual believes that the action will have no result in preventing a negative health condition, he or she is unlikely to take it. The fourth perception of the model, *perceived barriers*, argues that an individual usually makes a cost-benefit analysis in order to evaluate the benefits that he or she might get from making a preventive action and compare it with its expense (e.g., side effects, pain, costs, challenging and time-consuming). If the benefits outweigh the barriers, the individual is more likely to perform that action. Therefore, Rosenstock (1974) noted that "the combined levels of susceptibility and severity provided the energy or force to act and the perception of benefits (fewer barriers) provided a preferred path of action" (p. 332). Moreover, it was noticed that some stimuli were required to prompt the decision-making process (Janz & Becker, 1984). This is known in the model as "cues to action" which may be internal (e.g. symptoms) or external (i.e. mass media communication, awareness campaigns, personal interactions). However, this element was reported as the most underdeveloped aspect of the model and was rarely measured (Carpenter, 2010; Janz & Becker, 1984; Rosenstock, 1974).

The model has been successfully used to predict the adoption of different health behaviours, such as cancer screening, vaccinations and contraceptive behaviour (Harrison et al., 1992; Herold, 1983; Janz & Becker, 1984). It was particularly used to examine and predict the behaviour of diabetes patients (e.g. Alogna (1980), Burner et al. (2014), Burnet et al. (2002), Cerkoney and Hart (1980), Harvey and Lawson (2009), Janz and Becker (1984), Noh et al. (2020) and SA (2019)). Cerkoney and Hart (1980), for example, measured how patient with diabetes adhere to diabetes-related activities. They reported a significant correlation between the HBM overall measures and patients' overall compliance levels. In particular, 'cues to action' was reported to have the most frequent number of high correlations with compliance behaviour.

In conclusion, the HBM has proven to be an effective model in predicting and explaining health-related behaviour. It is one of the most used and researched health models. It has also been effectively applied in the context of diabetes. The model could, therefore, be usefully applied to the domain of this study since its main function is to help explain and understand patterns of health information behaviour of diabetes patients who use OSGs. To the best of the researcher's knowledge, the HBM has not been applied in the context of understanding health changes for people with T2D in OSGs. Information obtained from OSGs regarding diabetes might influence patients' health behaviour. This might lead to better illness-management and, as a result, patient empowerment. HBM elements can be used to understand this change and how patients perceive and act on information from OSGs. Therefore, HBM was adopted and applied in this study as Section 2.3.5 describes. The following section explains the Health Care Empowerment Model that will help in understanding empowerment's elements and factors that influence it.

#### ***2.3.4.4 The Health Care Empowerment Model***

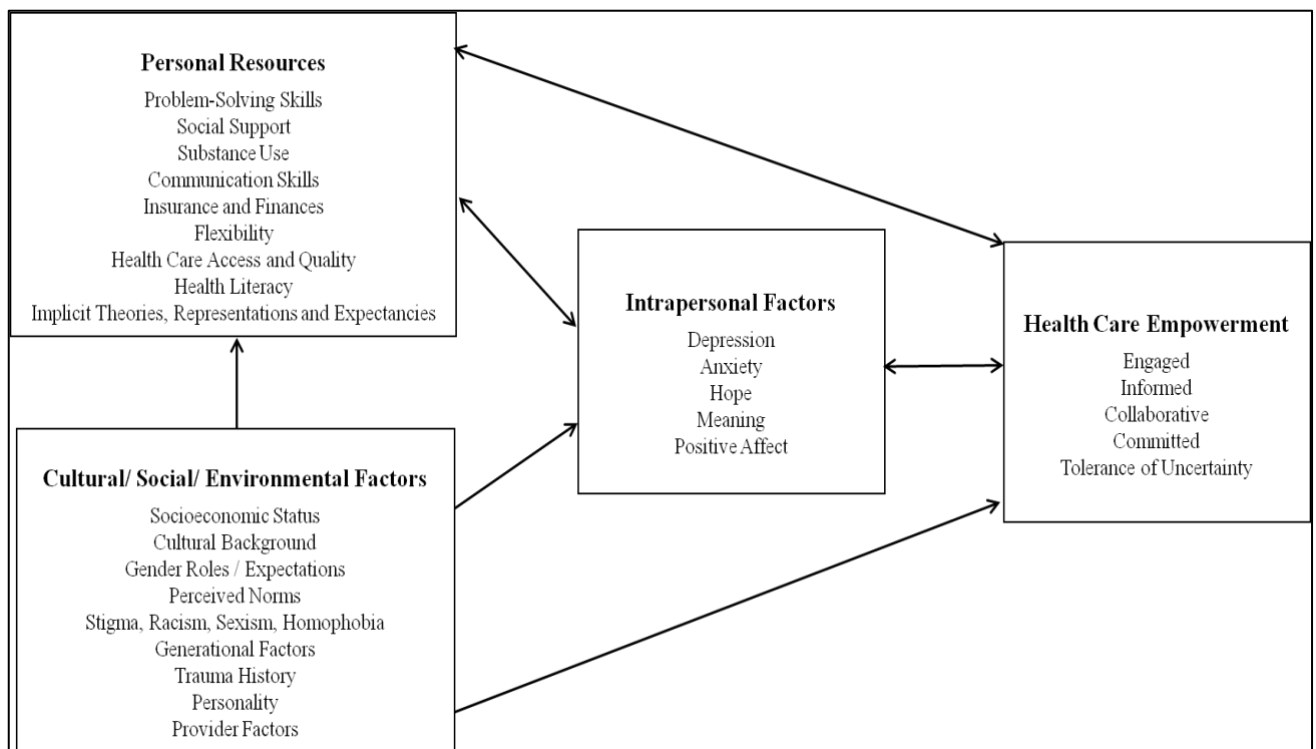
The term *empowerment* has been widely used in many disciplines, including economics, psychology, nursing, sociology and social work (Aujoulat, D'Hoore, & Deccache, 2007; Perkins & Zimmerman, 1995; Wallerstein & Bernstein, 1994). The use of the concept in a wide range of contexts resulted in a lack of development of well-articulated empowerment theories in health care (Aujoulat et al., 2007). However, the Health Care Empowerment model (HCE) was developed to fulfil the need for such framework. It was informed by the review of multiple articles of empowerment in health care as well as other social and health theories such as "the Social Action Theory, Stress and Coping Theory, Social Problem Solving Theory, and Health Belief Model" (Johnson, Rose, Dilworth, & Neilands, 2012, p. 1). Aujoulat, d'Hoore, et al., (2007), Aujoulat, Luminet, et al. (2007) and Aujoulat et al.

(2008)'s analysis of 55 articles related to empowerment informed the development of the model by introducing three main principles of empowerment in care that were used in building the model:

1. The goal of empowerment in care should not be seen as disease-specific but should aim to improve the overall psychosocial skills of patients.
2. Empowerment approaches are focused on patients and include experimental learning.
3. The authors (i.e. Aujoulat et al.) proposed a doctor-patient relationship that is focused on a reciprocal partnership between the two parties to enable empowerment.

The review of theories and empowerment-related studies uncovered the need for specialised theories and models in health care empowerment that articulate the main principles/ abstractions related to the phenomena. Therefore, the HCE model was developed to fulfil this gap in the literature by providing a cohesive construct that encompasses the human ability to effectively participate in health care in the most productive way possible (Johnson, 2011). As noted above, the model was developed based on various theories and studies and clinical experience.

The HCE model was developed by psychologist Mallory Johnson in 2011 to provide a framework that helps in understanding patient and health care providers in facilitating health care empowerment and identifying factors that contribute to optimal health outcomes (Johnson, 2011). It defines health empowerment as “the process and state of being engaged, informed, collaborative, committed and tolerant to uncertainties in treatment outcomes” (Johnson, Rose, Dilworth, & Neilands, 2012, p. 1). It is illustrated in Figure 2.2.



**Figure 2.2 Health Care Empowerment Model. Data Source: Adapted from Johnson (2011)**

As the model shows, the HCE level for an individual who is receiving ongoing medical treatment, is determined by a dynamic interplay of contextual factors, personal resources and intrapersonal processes. First, the contextual factors consist of elements that surround people in their daily lives and they make the largest group of factors to impact HCE. They consist of socioeconomic status, cultural background, gender norms and other factors. Additionally, they include factors that are related to health care providers and their training, culture, expectations and pressures. These factors are important because they directly influence individuals and their environment. For example, in some cultures, it is unacceptable to misbelieve doctors and, in others, females are branded as offensive when they choose to actively participate in providing health care services (Johnson, 2011).

Second, personal resources include elements related to social support, personal skills (such as problem-solving and communication skills), financial elements (e.g. holding an insurance and being financially stable), access to adequate health care, health literacy and expectations about health

(Johnson, 2011). For example, the availability and use of resources that facilitate HCE might be limited by the active use of drug and alcohol. In addition, individuals' representations and expectations about health, illness and treatment influence the role that individuals play in health care. The model suggests that these personal resources have an influence on HCE directly or indirectly through their effects on the intrapersonal factors.

Third, several positive and negative emotions that occur within the mind of an individual (e.g. hope and anxiety) form what is called in the model the intrapersonal factors. They have an immediate influence on the evolution of HCE as well as the use of personal resources. They are anticipated to influence HCE due to their direct effects on psychological, neurological and physiological pathways and indirect effects on treatment seeking and adherence, health-promoting behaviours and health care utilisation (Johnson, 2011). Thus, the intrapersonal factors hold a reciprocal relationship with HCE in the model.

As explained above, the model recognises HCE as the component of five descriptors/parts. First, patients should be engaged in health care. The first part of empowerment in the model describes the active participation in health care, including using extra materials, to maintain a high level of involvement in health care, accessing appropriate care and attending and preparing for appointments. Engagement in health care is considered as one of the most significant factors that lead to optimised health outcomes (Giordano et al., 2007; Mallinson et al., 2007; Mugavero, 2008; Tobias et al., 2007). The second part of HCE for an individual in the model is being informed. An empowered patient is expected to be aware of their health status, the illness, treatment options and the health care system including their rights and available resources. Third, empowered patients are collaborative with health care providers. Collaborative and involved patients in health care and decision-making are reported to have greater satisfaction and improved adherence to health care (Ballard-Reisch, 1990;

Brody, 1980; Kaplan & Frosch, 2005). Although there are some patients who prefer not to participate in their medical treatment, especially older patients (Cassileth et al., 1980; Swenson et al., 2004), the majority of patients prefer to play an active role (Kaplan & Frosch, 2005). Patients and care providers might have conflict over the decision-making process when patients believe that their preferences are not being met (Kremer et al., 2007). However, problems between patients and care providers and poor adherence to care might arise as a result of the lack of agreement on the level of shared-decision making between patients and care providers. In this case, patients might not acknowledge and validate the knowledge and expertise of the care providers (Johnson, 2011). Therefore, engaged and informed patients might not be seen as ideal by care providers unless they are collaborative. Fourth, empowered patients are additionally expected to be committed to their health and treatment. Johnson (2011) explained that patients who are engaged, but are not committed, might not follow doctors' instructions (e.g. disregard tests and procedures), which results in poor health outcomes. He added that "commitment enables engagement and collaboration with providers and facilitates adherence to collaboratively derived treatment plans" (p. 266). Committed patients are more likely to buffer against lapses in motivation after undesired illness progression, which allows more flexibility and acceptance of new treatment plans and realistic goals. Finally, considering how some illnesses are unstable, as well as the ambiguity in treatment, it is essential for patients to be tolerant of a certain level of insecurity. The necessity to manage uncertainty has been highlighted by many scholars as an essential task to cope with unpredictable illnesses (Brashers et al., 1999, 2004; H. Leventhal et al., 1984; Weinman & Petrie, 1997). Patients might face a huge challenge in balancing emotional needs and being rationally engaged in decision-making. Johnson (2011) suggested that a good balance can be achieved through "tolerating this uncertainty and proceeding with engaged, informed and committed treatment planning" (p. 267).

The model was tested and used in various studies and proved to help understand patients engagement in health care. For example, Sevelius et al. (2019) integrated the HCE model with the Model of Gender Affirmation to provide a powerful framework to understand factors influencing health outcomes of transgender women of colour living with the human immunodeficiency virus (HIV). Crouch (2014), on the other hand, used the model (with other methods) to investigate the influence of using electronic health record on patient activation for 40 veterans living with HIV. Compared to other methods used in the study, the model was found to be the best tool to understand the patients' behaviour.

In addition, various quantitative studies have been undertaken to test the model. For instance, Johnson, Sevelius, et al. (2012) examined the hypothesised factors of the model using data from ongoing HIV-related research. They provided support for the model in the context of HIV treatment. In another study, Van den Berg et al. (2016) performed path analysis on survey data from 1494 individuals living with HIV to evaluate the HCE model for adherence to antiretroviral therapy (ART). The study found that ART adherence was positively influenced by various factors from the HCE model, such as the patient-doctor relationship. In a longitudinal study, Wilson et al. (2018) assessed the relationship between empowerment as presented in the HCE model and 973 women living with HIV. The study concluded that the empowerment elements in the model (i.e. being informed, collaborative, engaged etc) were found to be promising pathways that could help promote engagement in care among the participants of the study. Lastly, Johnson et al. (2012) undertook a survey study on 644 HIV-infected individuals by applying exploratory and confirmatory factor analyses to investigate the model's validity. The findings showed that the model was helpful in understanding, measuring and tracking individuals' changes in how they engage with their health care. In particular, it helped in investigating the role of provider-related (e.g. HCP's perspectives and reactions) and contextual-related (e.g. cultures and genders) factors on empowerment. However,

Chiauzzi et al. (2016) explained that the causality path of these factors was not clear from the data. Although the model contributed to the literature by conceptualising the main concepts of empowerment in health care and their influencing factors, further work is needed to advance our understanding of how empowerment operates in health care. The model provides generic factors and static relationships between them that might not reflect what is happening in real life. Although the model is built on the principle that empowerment in care is not disease-specific, it was mainly focused on one condition (i.e. HIV) in one geographical context (i.e. the United States) in its development and testing. This might have missed other factors that might be present in other conditions that influence empowerment in care.

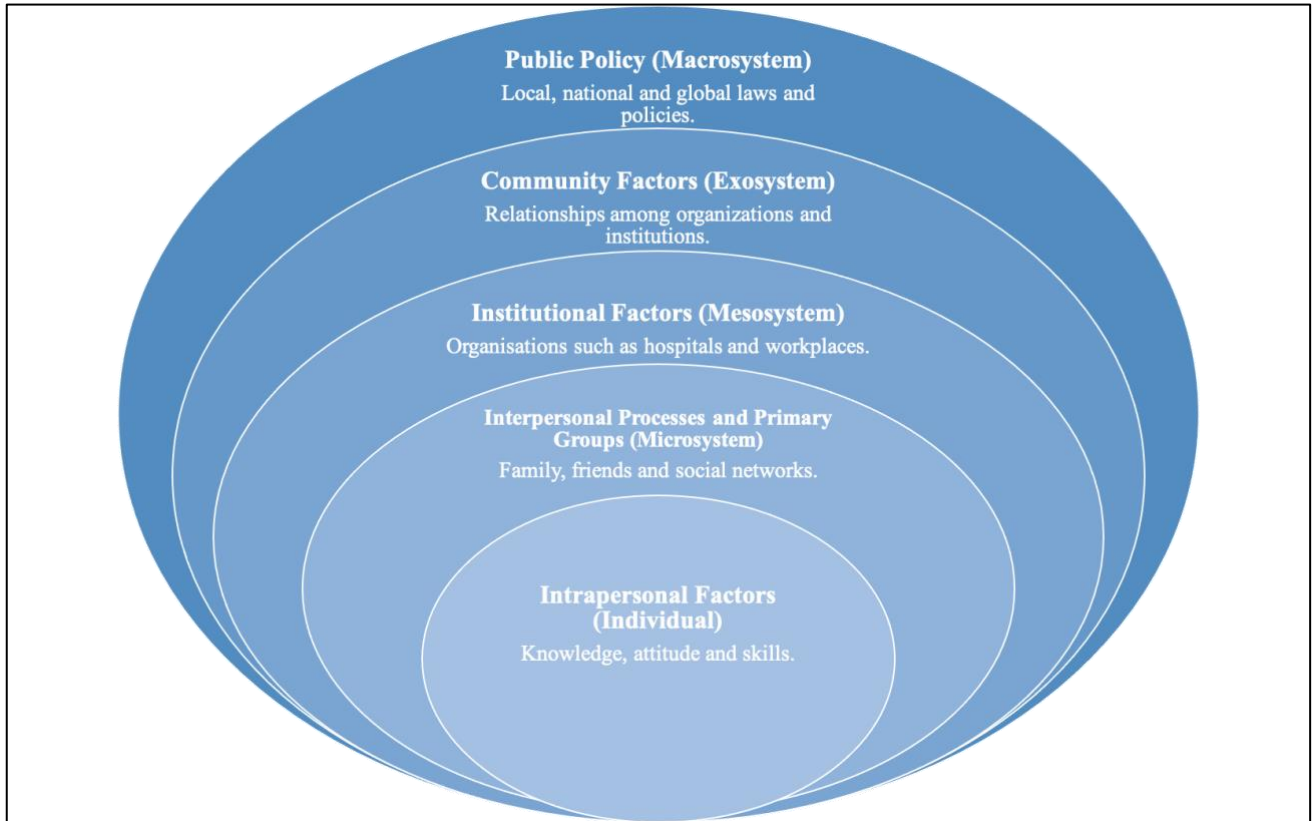
The HCE model offers a comprehensive framework for understanding health empowerment and the different factors that might affect it. Aside from the debate about how empowerment should be defined, which is discussed in Section 2.7, the model captures the main components of empowerment. The present study aims to investigate the role of using OSGs on people with T2D; therefore, the model was employed in the present study to explain how different factors on a patient's life (e.g. intrapersonal, cultural, and social factors) affect different empowerment components (e.g. engagement and commitment) and the role of OSGs in the change.

#### ***2.3.4.5 The Social Ecological Model***

The Social Ecological Model (SEM) is a theory that aims to understand personal and environmental factors that influence human behaviours (Bronfenbrenner, 1979). The model suggests that behaviours are influenced by and influencing various public policy, organisational, community, interpersonal and intrapersonal factors and the behaviour can be contextualised in these factors (McLeroy et al., 1988). It was first conceptualised in the 1970s by Bronfenbrenner (1977, 1979), then introduced as a formal theory in the 1980s to better understand human development (Bronfenbrenner, 1989). The



model is explained by locating the individual at the centre of surrounding influencing factors as explained in Figure 2.3 below.



**Figure 2.3 The Social Ecological Model. Data Source: Adapted from Bronfenbrenner (1977)**

As the model in Figure 2.3 shows, the behaviour of an individual can be influenced by five levels of factors and their interactions. The *macrosystem* level explains the influence of various local and global laws and policies have in the allocation and use of resources in health care (e.g. medical procedure) (Adamsons et al., 2007). The next level represents factors related to the community in which the individual is embedded (i.e., the *exosystem*). This includes the relationship among organisations and informal networks within the boundary of the individual. The *mesosystem* shows organisations and institutes and their rules for operation which influence the quality of the service provided to the individual. The next level (*microsystem*) is related to the formal and informal social network and support system that can affect the behaviour of the person such as family members and

friends. The last level represents the knowledge, characteristics, beliefs, attitudes and skills of the individual (McLeroy et al., 1988). The model suggests that the individual is affected by the collection and interaction of the factors (Bronfenbrenner, 1989).

The SEM has been widely applied in the promotion of various health behaviour interventions. For example, Leventhal and Brooks-Gunn (2000) used the model to explore the influence of neighbourhood residence on children and teenager well-being, and Vichayanrat et al. (2012) applied it to evaluate a multi-layered oral health intervention. More recently, Doyumğaç et al. (2020) utilised the SEM to understand online education during the COVID-19 pandemic, Parkman (2020) used the model to investigate youth physical activity engagement, and Kolff et al., (2018) employed the model to promote vaccination using technology. The model has shown its effectiveness in different disciplines in understanding the factors that affect people's behaviours (Arslan et al., 2020; Tanhan, 2019). The SEM has the potential to explain how various factors/levels influence the health and information behaviour for people with T2D using OSGs. Therefore, the SEM was utilised in this study to help understand the controversial treatment approaches users encountered in the OSGs as Section 2.3.5 shows.

#### ***2.3.4.6 Uses and Gratifications Theory***

The Uses and Gratifications Theory (UGT) was initially developed in the 1940s to understand the needs that radio communication fulfils and, since then, it has been largely used in mass communication studies to investigate why people prefer one medium over another to satisfy their needs (Katz et al., 1973; Weibull, 1985). The model suggests that individuals are aware of their needs and active in selecting and using media and their behaviours are goal-driven (Li et al., 2015). The theory explains various psychological and social needs that media uses can fulfil (Rubin, 2009). The UGT suggests that whilst different media seek to attract users, individuals tend to choose the

medium that gratifies their specific needs (Tan, 1985) including cognitive, emotional, social, personal or entertainment needs (McQuail, 1987). McQuail (2010) explained that the UGT is based on the following four main assumptions:

1. The selection of media and their content is driven by the goals and gratification of the users.
2. Media users are aware of their personal and social needs related to media.
3. Generally, the fulfilment of these needs plays a greater role in attracting users' attention than the cultural and aesthetic characteristic of the content.
4. Users' selection and formation of media channels can mostly be measured.

As new forms of media are developing, especially with the advancement of new technologies such as smartphones, people become more selective in choosing the medium that satisfies their needs which shows the importance of understanding their motivations (Ruggiero, 2000). The UGT has been widely used to understand the reasons for using various media and it showed its effectiveness in understanding the behaviour of media users.

Despite the successful application of the theory on various forms of media, the UGT has received several criticisms. First, the theory has been criticised for being too individualistic with a lack of consideration of the societal effects of media use (Elliott, 1974). Second, the UGT is mainly based on self-reports (i.e. data reported by individuals themselves), which might not reflect the actual behaviour since people might have different interpretations of their needs and satisfaction than the actual ones (Nisbett & Wilson, 1977; Rosenstein & Grant, 1997). Finally, the theory has been criticised for the inconsistent use of its concepts (e.g. the meaning of uses and gratifications) among researchers which might have resulted in fuzzy interpretations (Severin & Tankard, 1997).

The model has been applied to various forms of media to understand different behaviours including motivations to watch television (Weaver, 2003) and to use mobile phones (Leung & Wei, 2000). The theory was also found to be useful to research the Internet and new media communications (Morris & Ogan, 1996). For instance, it was successfully employed to understand users' behaviours on the Internet in general (Yoo & Robbins, 2008) or in specific online platforms such as Twitter (Alaslani, 2019; Cozma & Dimitrova, 2020), Facebook (Azizah, 2020) and health OSGs (Xu & Liu, 2019). The UGT was used in this study to understand users' behaviour in OSGs as the next section explains.

### ***2.3.5 Summary of the theoretical framework***

Section 2.3.4 outlined the key theories and models related to this study. This section provides a summary of the theories and models adopted in the present study and explains how they were applied.

First, since patient empowerment has been defined and interpreted differently by various scholars (as explained in Sections 1.2.3, 2.3.4.4 and 2.7), the HCE model was seen as a comprehensive framework that captured the main constructs of patient empowerment, explaining how they are influenced by other factors. As explained in Section 2.3.4.4, the model explained that patient empowerment is the state and process of five constructs, and that they are affected by an interplay of various contextual and intrapersonal factors as well as different personal resources. This interpretation of the concept of patient empowerment provides studies investigating patient empowerment with an in-depth understanding of the concept and its surrounding influencers. The present study, therefore, employed the HCE model as a framework to understand empowerment in the context of the study. In particular, it aimed to investigate the role of OSGs in empowering people with T2D as outlined by the HCE model. The study formulated one of the research questions (Section 2.10) based on the influencing factors outlined by the HCE model. These factors and the

empowerment construct reported by the model were seen as comprehensive and appropriate for the present study as they explain that patient empowerment is presented and influenced by the sum of various elements. This framework allowed the researcher to investigate the phenomena from an inclusive angle of all possible factors that may influence the empowerment of people with T2D using OSGs. As a result, the findings of this study showed that various factors affected the state of empowerment for the members and participants of the study (see Chapter 6). The thesis also contributed to the model with a new set of factors that were found to influence patient empowerment (Section 6.4). The model was effective in providing a comprehensive framework about patient empowerment for the present study that helped to investigate and understand the phenomena from various perspectives.

Second, the HBM explains and predicts health-related behaviours. When seeking information from other OSG peers, the model has the potential to explain why some behaviours were adopted and others were not. The HBM is based on various constructs that provide insights in how OSG users may behave when encountering different information in the OSGs. The model, therefore, was utilised to interpret some of the findings. For example, Sections 4.3.2, 5.3.2.2.1 and 6.2.1 used the model to understand the factors that motivated OSGs users to seek information and think about modifying their behaviours or up taking new ones. The model was helpful in providing insights about how and why individuals differed in their behaviours. The findings of the current study supported the inclusion of some constructs (i.e. perceived self-efficacy and self-involvement) to the model as the study showed their importance in motivating the users and participants to change their behaviours (Section 6.2.2).

Third, the SEM explains that the behaviour of individuals may be influenced by the complex interplay of various personal and environmental factors. These factors included public policies,

organisations, interpersonal and intrapersonal factors and the relationships among them. The model was utilised in the present study to understand the controversial treatment approaches exchanged between OSG members. The model was effective in providing in-depth insights about how and why these controversial approaches were present and how they influenced OSG members as explained in Section 4.4.2.

Fourth, three other theories and models were used to interpret various findings. In particular, the TTM was used in Section 4.4.3 to understand how OSG members differed in their needs based on their stage of change as explained by the model. The SCT, on the other hand, was utilised in Section 6.3 to understand how less-engaged OSG users changed their behaviours and values regardless of their engagement level in the community. Finally, the UGT was employed to understand the needs that OSGs satisfy for various user roles identified in the study (Section 6.3). The three theories and models helped to provide an in-depth understanding and interpretation of the findings.

In conclusion, the study employed various theories and models to design the study, inform the analysis and interpret the findings. The HCE model was the main framework in the study that was used to understand and investigate empowerment for people with T2D using OSGs in the UK. The HBM was effective in explaining how members and participants behaved differently in adopting or motivating their behaviours. The SEM was successful in understanding how controversial treatment approaches encountered in OSGs were present for the members of the study. Other theories and models, including the TTM, SCT and UGT, were employed to understand better the various findings. The use of various theories and models in designing the study and interpreting the findings allowed the researcher to optimally investigate the research questions and interpret the findings. The following section introduces health literacy and discusses its main components.

## 2.4 Health Literacy

The term health literacy was introduced in the 1970s (Simonds, 1974) and, since then, it has gained an increasing interest in health care. The term has many definitions (e.g. Kindig et al., 2004; and Sørensen et al., 2012); however, the definitions have focused mainly on describing the skills that help people to access, understand, value and use information that will affect their health (Nutbeam & Lloyd, 2021). One of the widely used definitions was that developed for the National Library of Medicine which defined health literacy as: “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Kindig et al., 2004, p. 4).

To understand the term *health literacy*, Sørensen et al. (2012) proposed a model that integrated different views/definition of health literacy in the literature. This integrative model was the result of reviewing 17 definitions and 12 conceptual models of the term from various medical and public health authors in the literature. The model presented 12 dimensions of health literacy applied in three domains (i.e. health care, disease prevention and health promotion). The model positioned four dimensions, relating to accessing, understanding, appraising and applying health information at the core of the model and explaining that each of them requires specific cognitive qualities, as explained in the following:

- **Access:** describes one’s ability to seek, acquire and obtain health information. This dimension usually depends on one’s belief in the need to access information, timing and trustworthiness.
- **Understand:** refers to the capacity to comprehend the accessed information. It depends on one’s expectations, perceived benefits and individualisation of the outcomes and interpretations of the consequences.

- Appraise: refers to the ability to explain, filter, judge and assess the accessed health information. It mainly depends on how complex the language of the accessed information is and how much of it is understood.
- Apply: describes the ability to use the information to make decisions to maintain and improve one's health. The effective application of the accessed health-related information depends on comprehension.

The model also included social, environmental and personal factors that might influence health literacy, such as the use of health services, their cost, an individual's health behaviour, background, empowerment and participation. The model stresses that health literacy is applied in three main domains: health care, disease prevention and health promotion in individual and population levels. For example, in the domain of disease prevention, when the COVID-19 pandemic emerged rapidly, individuals and communities differed in how they applied health information and adapted to new behaviours. This showed that health literacy is a critical instrument for the prevention both communicable and non-communicable diseases (Paakkari & Okan, 2020).

As the various definitions of the term suggest, health literacy comprises a set of skills that differ between individuals. Even people with a high level of skills might face challenges in applying them in unfamiliar, and potentially intimidating, settings (e.g. in hospitals with HCPs) (Berry et al., 2017). In addition, although the literature explains that health literacy refers to the capability of individuals to cope with the complicity of health services in modern society (McQueen et al., 2007; Peerson & Saunders, 2009), the exact nature of the competencies required to meet these demands is still debatable (Walters et al., 2020). When explaining these competencies, some authors have focused on various skills and capabilities at individual levels that take place in a medical context. They refer to as "patient health literacy" (Ishikawa & Yano, 2008), "medical health literacy" (Peerson & Saunders,



2009) and “clinical health literacy” (Pleasant & Kuruvilla, 2008). On the other hand, others focus on a broader view of these competencies which are applied in the social realm and refer to it as “public health literacy” (Freedman et al., 2009).

In conclusion, the concept of health literacy was introduced and its main components were discussed in this section. The section explained that health literacy is applied at different levels and is crucial to maintaining, preventing and promoting various diseases. As Sørensen et al’s model explained, health literacy influences people's health empowerment and is determined by multiple personal, social and other factors.

The following section provides an overview of the four types of Diabetes.

## **2.5 Diabetes**

### ***2.5.1 Types 1 diabetes***

Thompson et al. (2015) explained that Type 1 diabetes occurs when the cells that produce insulin, which are located in the pancreas, are attacked by the immune system. For unknown reasons, the attack destroys the cells that produce insulin and causes diabetes. Over time, the cells will not be able to produce insulin anymore. Type 1 usually starts in childhood or young adulthood and it cannot be prevented (Thompson & Lau, 2015). American Diabetes Association (2020) reported that genetic and environmental factors play a key role of having diabetes Type 1. They explained that the risk of having Type 1 diabetes increases if any family members had or have it. Being unusually thirsty, unreasonably losing weight, urinating frequently, having blurred vision and being hungry most of the time are the main symptoms of both Type 1 and 2 diabetes (Thompson et al., 2015). Patients with Type 1 commonly suffer from low blood sugar level (known as hypoglycaemia), which can lead to many symptoms such as quick heartbeat, unexpected mood change, shaking, sweating or loss of

consciousness (Nall & Cirino, 2016). Patients of Type 1 diabetes are treated by taking insulin injections that help them to keep the blood sugar within the normal range.

### ***2.5.2 Type 2 diabetes***

T2D occurs when there is no sufficient amount of insulin in the blood or when the cells do not efficiently react with the produced insulin (NHS, 2016a). Many patients with T2D are obese or have high body fat in the abdominal area (American Diabetes Association, 2014). Even though Type 2 is mostly present in adults, it can be developed at any age (Thompson & Lau, 2015). Type 2 can be overcome if treated properly in early stages by following healthy habits and lifestyle like exercising regularly, having a normal weight and eating healthy (Thompson & Lau, 2015). Both Type 1 and 2 diabetes, if not managed well, can lead to other health complications, such as heart disease, stroke, blindness, kidney failure and foot or legs amputations (Thompson & Lau, 2015). Treatments for diabetes Type 2 include eating healthy, exercising and testing the blood glucose level regularly (Centers for Disease Control and Prevention, 2015). Some patients may also need to take oral medications, such as insulin, to maintain a healthy amount of insulin in the blood.

### ***2.5.3 Gestational diabetes***

Gestational diabetes mellitus (GDM) is the third widely prevalent form of diabetes (National Institutes of Health, 2016). GDM is caused when pregnant women have a high blood glucose level during pregnancy, usually starting at 20 weeks of pregnancy (McIntyre et al., 2019). Because of the embryo, pregnant women require double to triple the usual amount of insulin (Diabetes UK, n.d.-b). Failure to produce the extra amount of insulin causes GDM. According to DeSisto, Kim and Sharma (2014), GDM usually disappears after the pregnancy but both women who have had GDM and their born children are more likely to develop T2D in the future. They are also more likely to develop GDM in future pregnancies (NHS, 2016a).

#### ***2.5.4 Other types of diabetes***

There are also less common types of diabetes, such as LADA, MODY, double, steroid induced, brittle and secondary diabetes. LADA (latent autoimmune diabetes in adults) diabetes is considered as a subgroup of Type 1 diabetes but also shares some of the characteristics of T2D; therefore, it is sometimes called Type 1.5 diabetes (Carlsson et al., 2000). It can be described best as a slow progression of Type 1 diabetes (Gebel, 2010). Unlike Type 1 and 2 diabetes, which are polygenic, monogenic maturity onset diabetes of the young (MODY) is an inherited type of diabetes caused by mutations in a single gene (National Institutes of Health, 2007). MODY is commonly linked to Type 2 since it shares some of its symptoms. However, MODY is not linked to overweight and most of its patients are newborns or young children (National Institutes of Health, 2007).

Diabetes is a complex condition which can be the cause of additional health conditions. Scientists have shown that having T2D might increase the risk of developing Alzheimer's disease in the future (Kroner, 2009).

Having summarised the different types of Diabetes, the following section discusses digital information resources.

### **2.6 Digital Information Resources**

The Internet is a major resource for health information seekers. It is a rich source of information and a cost-efficient communication medium (Moolla et al., 2019). It provides structured and easy-to-use platforms where users can communicate and exchange information. It is an effective empowerment tool for patients with diabetes and a very important source of information to manage their illness (Lambrinou et al., 2019; Longo et al., 2010). According to the UK Office for National Statistics,

nearly 96% of households in the UK had access to Internet in 2020, with 89% of daily or almost daily usage. The most common activities the Internet was used for in the UK in 2020 were: exchanging emails (85%), exploring information related to goods and services (81%), accessing online banking services (76%) and searching for health-related information (60%) (The Office for National Statistics, 2020). A study conducted on Internet users showed that eight in ten Internet users went online to find information related to their health (Laugesen et al., 2015; Shahab et al., 2014), resulting in the third most common activity on the Internet that year (Fox, 2011; Gonzalez et al., 2016).

Having a chronic illness, such as cancer and diabetes, is a journey that can last for the remainder of a person's lifetime. A chronic illness can be defined as any condition that lasts for a long period of time (e.g. Adams et al., (2013) suggested three months or longer), does not have certain cure and might largely impact the life of the person (Petrie & Jones, 2019). The population of chronic patients is enormous; for instance, 60% of U.S. adults were diagnosed with at least one chronic disease in 2020 (National Center for Chronic Disease Prevention and Health Promotion, 2020) and approximately more than 15 million people in England were reported to have at least one chronic illness (National Institute for Health and Care Excellence, 2020). Since such conditions require permanent care, they account for approximately 50% of general practitioners' appointments and 70% of health care spending (The Department of Health, 2012). Patients with these conditions, as well as their friends and family members, may go online in order to seek and share information, experiences and stories, network with others, support other patients and search for information (Chen et al., 2019; Househ et al., 2014). For example, Madrigal and Escoffery (2019) reported that among 401 Internet users who have at least one chronic illness, 75% of them searched the Internet for health information.

The Internet has been used in the health domain in two fields: to seek information and connect with others that have the same health condition (Park & Kwon, 2018). For the purpose of the focus of the research, online support groups are highlighted and discussed below as a medium to exchange health information and offer support for other peers.

### ***2.6.1 Health support groups***

To provide an understanding of health support groups, both face-to-face and online support groups will be discussed in the next sections.

#### ***2.6.1.1 Face-to-face support groups***

As described in the previous Chapter (Section 1.2.2), it has been reported that support groups started back in the 18<sup>th</sup> century in a psychiatric hospital in Paris and have re-emerged throughout history since (Davidson et al., 2012). In the 1980s, support groups became increasingly popular (Heller et al., 1997). They are an informal resource that was found to provide curing components to a large number of conditions. There is a wide range of support groups for many conditions such as weight loss, medical, mental, life transitions and addictions support groups. Through such groups participants get to know new techniques to handle health problems, overcome challenges and maintain new behaviours (Pledge, n.d.). The mutual support found in these groups is unique and powerful and can induce lasting impacts (Pledge, n.d.). Support groups can be either individually or professionally operated. Individually operated groups (sometimes called mutual self-help groups or peer-to-peer support groups) are fully organised by their members. The members are usually volunteers who have had a personal experience with the groups' subject and focus (Kelch, 2014). Peer-to-peer support groups offer the kind of help that professionals may not be able to provide, such as emotional support, friendship and experiential knowledge (VandenBos, 2007). Professionally operated groups are created and managed by professionals such as doctors, social workers or member

of religious organisations. Professionals of this type of groups control discussions and provide advice, and act as what is known as moderators for the group.

Support groups can be very useful and their effectiveness has been proven by many studies (Alison Faulkner & Basset, 2012; Hardy et al., 2019; Heller et al., 1997; Seebohm et al., 2013). Since doctors have a limited time for each patient, support groups are valuable resources for patients because they can receive support from other members and share their personal stories. It has been shown that social support can be obtained through sharing similar experiences (Sanger et al., 2019a; Zhu & Stephens, 2019) and it can decrease the amount of pain for patients (Holtzman et al., 2004). Peer support have the potential to help patients break their loneliness and promote their recovery (Jadwisiak, 2020). In addition, meeting other people who have similar health interests can increase patients' knowledge and make them more empowered (Masi et al., 2003; Sharma & Khadka, 2019). Participating in support groups allows patients to also provide help to other peers, which can have a positive effect on helpers' psychological well-being (Hanniball et al., 2019; Riessman, 1997).

Nevertheless, support groups can have negative effects on participants too, like a rise in depression or fear of an illness and its consequences (Kolawole, 2019; Uden-Kraan, 2008). This may be the result of reading other members' negative emotions or experiences (Cohen et al., 2000). It also might be a result of unwanted advice which can affect patients negatively (Holtzman et al., 2004; Kolawole, 2019).

Although face-to-face support groups have shown positive results, researchers have reported these groups having less than expected participants (Bauman, Gervey, & Siegel, 1993; Hamann et al., 2000; Uden-Kraan, 2008). This was associated with geographical distance issues (Bauman et al., 1993) which can be overcome via the Internet.

### ***2.6.1.2 Online support groups (OSGs)***

The development of online communities that allow many members to communicate started back in the 1970s in a small-size research and development project (Woolley, 1994). Communications can be synchronous or asynchronous. Synchronous channels allow members to exchange messages instantly, such as chat rooms. On the other hand, asynchronous channels forward messages to all group members and email lists are a clear example. The popularity of a specific channel changes over time. For example, email lists were dominant in the late 1980s, whereas, web-based forums were reported to be leading online discussion groups in the 2000s (Potts, 2005). Most of the studies that looked at patients' use of online communities from 2000 to 2012 focused on web-forums (66.6%), which shows its popularity as a favourite communication channel between patients (Hamm et al., 2013).

OSGs are created to gather people with similar health conditions in one virtual space. Potts (2005) reported that OSGs date back to 1982 and defined them as “online communities for those affected by a common problem, in particular those related to health or social circumstances” (p. 1). They offer health information and mutual support. Some OSGs are owned by, or connected to, health organisations while others are independent. Most of them were created by regular people and not by medical professionals (Potts, 2005). They cover almost everything, from well-known conditions, like lung cancer, to very rare ones, like Zollinger-Ellison syndrome. There are also support groups that are designed for specific niches, like lesbians with breast cancer or people from Latin America with alcohol-related problems. Other groups are designed to target patients' family members or friends, such as support groups for families with disabled children. Researchers have studied OSGs to get more insights on how they have been used (Attard & Coulson, 2012; Xu & Liu, 2019), their impact (Fullwood et al., 2019; Lieberman et al., 2003), gender differences on OSGs (Blank et al., 2010;

Ihrig et al., 2020; Nagler et al., 2010; Pan et al., 2019), their effects on the patient-doctor relationship (Audrain-Pontevia & Menvielle, 2018; Oh & Lee, 2012) and how the beliefs in such groups were formed (Sanger et al., 2019b).

Patients use OSGs to fulfil their health information needs that cannot be achieved by health providers, not to circumvent them (Rupert et al., 2014). Doctors tend to spend an average of 13 to 16 minutes with each patient (Peckham, 2016). Therefore, patients may not receive sufficient information, and may find themselves not fully aware of their illnesses, available treatment options or treatments' consequences. While patients prefer to be informed about all care options and consequences, doctors face difficulties in expressing them and tend to filter patients' information (Smailhodzic et al., 2016). Smailhodzic et al. (2016) also reported that patients think doctors might not be aware of new developments in medicine, for example, new treatments or technologies, so patients go online to explore new discoveries. The researchers found that patients are occasionally not satisfied with their care providers because they are unable to provide emotional and informational support. Therefore, patients stated that social support, which includes emotional, information and network support, is the main reason of participating in online support sites. That includes using the sites to express patients' emotions and compare how bad or good their situations are (Smailhodzic et al., 2016). OSGs have many advantages, as well as limitations, which will be discussed in detail in the following section.

### ***2.6.1.3 Benefits and drawbacks of online health communities***

Patients' use of the Internet to obtain health-related information has multiple advantages and disadvantages. The following points summarise the benefits of using the Internet as a source to obtain health information:



- Decreasing cost and maximising convenience for patients. This includes: saving patients' time, demanding less effort from the patients, not requiring them to be present at a specific facility (Ren et al., 2019). Gustafson et al. (1994) reported that some breast cancer patients used the Internet to help them with their health conditions because of their lack of money for a second medical opinion.
- Finding help when feeling stigmatised or embarrassed. The Internet is a powerful means for reaching patients suffering from conditions that make them feel stigmatised or embarrassed (Pan et al., 2019; Sundström et al., 2017). Griffiths et al. (2006) reported a number of conditions that are considered to be in this category, such as mental health problems, T2D and AIDS. Patients recovering from sexual abuse or AIDS might find online support groups more convenient to discuss sensitive matters (White & Dorman, 2001).
- Reducing isolation. The Internet has covered very large geographical areas which are not covered by medical providers. Therefore, it can reach people who are geographically isolated or not have appropriate medical services where they live (Li et al., 2020). In addition to geographical isolation, Griffiths et al. (2006) reported other types of isolation. For example, it is not easy for people with Alzheimer's disease, disabilities or mothers with children at home to go out and seek medical advice and support at any time. Moreover, the Internet helps patients in finding others with similar health conditions, which helps them in facing the illness and not feeling lonely. The Internet becomes more important when the health condition is rare. In these situations, online communities might be the only way to find others in a similar situation (Tonsaker et al., 2014).
- Providing immediate information in emergencies. When a health crisis occurs to a person, for example, when a child becomes ill, the Internet can be a very helpful source of information since it provides a continuous access to the needed information (Pan et al., 2019).

- Finding a range of information. Patients reported that the Internet allowed them to discover a wide range of medical opinions around the globe (Vilhauer, 2014). They stated that they followed new medical experiments related to their diseases that were taking place in other geographical locations to know the best treatment options for their conditions.
- Offering an equal space. In online communications, gender, race, sexual orientation, religion, disability, colour, ancestry, nationality, weight, social status, appearance and age are not identified unless users state them. Rheingold (1993) pointed out that people with disability find online spaces easier to establish new friendships. These spaces meet their needs and treat them the way they want to be treated. Rheingold (1993) illustrated that people on online societies treat disabled people's feelings and thoughts equally without considering the way they walk or talk. He stated that hiding people's characteristics creates free, open and equal societies.
- Having immediate and constant support. Patients expressed that they could find support through online communities even late at night when they were suffering and could not sleep (Vilhauer, 2014). When their family and friends are not available, they could find support in virtual communities (Sharf, 1997). In addition, the fact that they can keep a copy of the support conversations and tips and can reread them at any time made them feel happy.
- Not feeling stressed. Online communications enable patients to express their feelings freely and clearly without being under any pressure. Unlike face-to-face support groups, computer-mediated communications allow patients to think about what they want to say and type it without being afraid of others' reaction or being wrong (Vilhauer, 2014).
- Forming and arranging campaigns. Digital spaces have been used to form social and political movements related to a particular health cause or disease (Sundström et al., 2017; White & Dorman, 2001). Local, national and international organisations have been affected by such movements (Feenberg et al., 1996). Campaigners expressed their concerns to authorities,

demanded changes to certain health policies or services or required to re-prioritise certain projects.

Even though online communities have multiple advantages, they have drawbacks and limitations too, such as:

- Requiring access to the Internet. Although the Internet has spread around the world, there are still difficulties to access it in certain areas or for specific groups of people. This might be associated to the lack of infrastructures or lack of money. In certain places, governments restrict the access to the Internet and make it difficult to reach online communities. Therefore, the United Nations (2016) considered that having an Internet access and being able to freely express opinions online as one of the human rights. To overcome this limitation, some governments offer free Internet access in public libraries. In the United States, for example, almost all public libraries offer free public access to computers and to the Internet (American Library Association, 2009). Also, in the UK, many libraries offer computers and Internet access, mostly for free (UK GOV, 2017).
- Being literate. This includes traditional and digital literacy. To access and participate in online communities, users need to be able to read, write and use computers, tablet or smartphones.
- Having overwhelming information. Since a large number of people can post on online spaces, some members found reading these posts as too time-consuming (Han & Belcher, 2016).
- Misunderstanding information. Computer-mediated communications lack, or have very limited, facial, visual and emotional expressions. Therefore, they might be misinterpreted. To overcome this issue, many online members use emoticons to convey their feelings (Wirza et al., 2020).
- Lack of trust and accuracy. The public can participate in online communities without verifying their identities. This makes it hard to develop trust in online communities (Vohra & Bhardwaj, 2019; Zulman et al., 2011). In addition, there are people who have financial and other interests in recommending specific treatment options, or may try to fraudulently obtain money by deception.

Therefore, various websites have set guidelines to evaluate health information (Hernández-García & Giménez-Júlvez, 2020; Winker et al., 2000).

- Lack of information privacy. In general, information privacy refers to “the claim of individuals, groups, or institutions to determine for themselves when, how, and to what extent information about them is communicated to others” (Westin, 1968, p. 7). Solove (2005) classified information privacy problems into four key types: information collection, information processing, information dissemination and invasion. Each type contains a number of activities that may violate information privacy. In information processing for instance, data linkage, which refers to the collection of a person’s information from various sources, combining them together, and analysing them to get greater insights about the individual, is an activity that may violate a person’s privacy (Solove, 2010).

OSG users, as a form of Internet users, are exposed to these four information privacy problems. They share some of their personal data, either during the registration process (e.g. email, phone, personal picture, date of birth), or while building their profile (e.g. treatment history, treatment plan, medications, health provider information) or when posting in the OSGs, and such data might be stored permanently (Li, 2013). This data could be processed or aggregated with browsing cookies, Internet Protocol addresses (known as IP addresses) and other data to build user profiles to be used in advertising products and services (Huesch, 2013; Rowan et al., 2017). Data from different sources might be linked by using data mining technologies to produce valuable personal data aggregates (Li, 2013). The data also might be shared with third parties, including medical and pharmaceutical companies, researchers, insurers, employers and non-profits organisations, without obtaining explicit consent (Li, 2015; Williams, 2010), although there have been recent laws in certain countries, such as the General Data Protection Regulations (GDPR) in the EU and UK to prevent this. In a study of 120 websites, including health websites, 56% of them leaked personal users’ data to third parties with the percentage increasing to 75%

when including user identifying information (such as the IP address) (Krishnamurthy et al., 2011). In the same study, health websites showed the highest percentage of leakage (9 of 10 websites). Another study of 20 health websites showed similar results, with 13 of them being leaked (Huesch, 2013). Although the European GDPR aims to stop such unauthorised use of the data (Voigt & Von dem Bussche, 2017), there is the risk that the data might be hacked and leaked from the main website or from a third party website (Williams, 2010).

While most health websites briefly list how users' data might be used in their terms and conditions (T&Cs) and privacy policies, previous studies showed that most online health information users are not always happy with the quality of this documentation (Ahmed et al., 2020; Angst, 2009). One study showed that only 27% of online users reads the T&Cs and just 10% understood them (Glancy, 2014). Social networking sites, including OSGs, are reported to have complex privacy policies due to the extensive interactions they offer (Kienle et al., 2008; Obar & Oeldorf-Hirsch, 2020). Health social networking sites might additionally contain complex health language, which requires high level of education to understand them (Ermakova et al., 2015; Glenn & Monteith, 2014; Meiselwitz, 2013; Savla & Martino, 2012). Even though users are concerned about the T&Cs and privacy policy of a website, they have no option but to accept them (Li, 2015), otherwise, they would not be able to benefit from the site and fulfil their needs.

While there are various government data protection laws in place to protect online users and health information in many countries, such as the Data Protection Act (1998) in the UK, the HIPA (1996) Act in the USA and the new General Data Protection Regulation (2016) in the European Union, there are still challenges in applying such laws (Binns, 2017; Esteve, 2017; Kuner et al., 2017).

- *Trolling.* Trolls are online users who “post inflammatory comments, insults, abuse or hateful remarks” (Dosani, Harding, & Wilson, 2014, p. 4). They tend to attract users’ attention and lure them into pointless and laborious discussions (Herring et al., 2002; Hilvert-Bruce & Neill, 2020). Komaç and Çağiltay (2019) explained that revenge, boredom and attention seeking are the leading reasons for trolling. Schwartz (2008) argued that trolls can only be stopped when other online users ignore them. Trolling in online communities might result in loss of trust among the community members, discussion distraction and other indirect consequences (Herring et al., 2002). To reduce the harm of trolling to their users, some OSGs provide 24-hours moderation of the discussions and the removal of trolls’ membership from the website (Dosani et al., 2014). The topic and nature of the OSGs can determine how serious the effect of trolling is for that group (Herring et al., 2002; Sugiura & Smith, 2020). For example, in emotional and sensitive OSGs, such as those for mental health issues and victims of sexual abuse, trolling is a serious concern that needs to be addressed to have a safer environment for the users.
- *Defamation.* Although online communities allow users to express their emotions and share their experiences positively, users may also use them to defame other people (e.g. doctors) and institutions (e.g. clinics and hospitals) (Lim, 2016). Defamers use free and uncontrolled spaces to harm the reputation of others unjustifiably (Grobler & Dhali, 2016), which might result in loss of employment, exposing others to derision or questioning the public’s confidence in them (Lim, 2016).
- *Cyber-attacks.* Since users and their personal information are present in online spaces, they are exposed to the risk of malware attacks, which aim to gather users’ information and

damage their computers (Kayes & Iamnitchi, 2017). Users are additionally at the risk of other cybercriminal attacks, such as identity theft, fraud and phishing<sup>2</sup> (Rathore et al., 2017).

- *Cyber harassment*. This refers to using Internet communication technologies to send abusive and threatening messages to other online users (Burke Winkelman et al., 2015). OSG users face the risk of online harassment when communicating with other peers (Naslund et al., 2016). This is especially important for vulnerable users, such as people who suffer from mental illnesses, who might have greater negative impacts from these attacks (Alhaboby et al., 2017).
- *Cyberstalking*. Online communities provide excellent platforms for some people to gather information about others and cyberstalk them (Worsley et al., 2017). Cyberstalking has many definitions, but researchers have highlighted the action of using electronic devices to track certain people repeatedly as the most prominent characteristic (Al-Khateeb et al., 2017; Reynolds et al., 2012; Stevens et al., 2020). The main difference between cyber-harassment and stalking is that the latter tends to target a specific individual or group of people (D'Ovidio & Doyle, 2003) whereas cyber harassment might target unknown online users to the attacker. Cyberstalkers use Internet means to perform unwelcomed contacts, harass others, express unwanted sexual attention and threaten others with violent activities (Reynolds et al., 2012). Cyberstalking is considered as a serious criminal problem and laws have been developed to protect online users (Marcum et al., 2017).

In the following section, patient empowerment definition and its related concepts will be discussed.

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<sup>2</sup> Phishing is the deceitful attempt to acquire sensitive information on the Internet by impersonating as a trustworthy organisation/ individual.

## **2.7 Patient Empowerment**

In Section 2.3.4.4, the main constructs of empowerment have been outlined and discussed. This section outlines the concept of patient empowerment, the main differences between empowerment and other terms, empowerment's main principles in diabetes care, the main differences between empowering treatment model and the traditional model and the main studies that have investigated empowerment in OSGs. The discussion starts with empowerment in health, in general, then it applies it in relation to diabetes care.

### **2.7.1 What is Empowerment**

As explained in Chapter 1, patient empowerment refers to the process of making patients knowledgeable, self-aware and responsible for their own health. It has been the subject of considerable investigation and speculation among health researchers (Oh & Lee, 2012).

Empowerment should be the purpose of patient education (Anderson & Funnell, 2011; Freire, 2000). However, researchers have struggled in reaching a general agreement on empowerment and detecting the moment of being empowered since the concept lacks coherence in accurate definition and measurement (Gibson, 1991; Zimmerman, 1995; Broom, 2005; Gutschoven & Van den Bulck, 2006; Barak et al., 2008; Oh & Lee, 2012).

Traditionally, empowerment was viewed as a process that enables disadvantaged people to gain mastery over their lives (Oh & Lee, 2012). It refers to a concept imprinted many decades ago in the context of strengthening minority groups (Barak et al., 2008). Empowerment was perceived as a group action and linked to social reform that fight to address inequalities (Anderson, 1996; Staples, 1990). Relatively lately, empowerment literature focused on empowering individuals (Gutschoven & Van den Bulck, 2006; Halvorsen et al., 2020; Menon, 2002; Oh & Lee, 2012). It consists of various dimensions (such as social and political) (Breton, 1994; Cowger, 1997; Rappaport, 1987; Tanima et



al., 2020). Barak et al. (2008) explained that, at individual or psychological level, “empowerment entails both perceived capabilities in coping with various challenges and the perceived ability to overcome obstacles” (p. 1869). At this level, empowerment involves a person’s ability to act effectively to reach desired results (Boehm & Staples, 2002). By broadening the concept of empowerment to individuals rather than restricting it to groups, the term includes various experienced personal factors such as the ability to think critically, make personal decisions and access related resources (Wallerstein, 1992).

### ***2.7.2 Empowerment Distinction***

The term empowerment has been often used interchangeably with other terms, such as patient involvement, engagement, enablement, participation and activation, which makes it difficult to identify and measure. However, scholars have reported that the term empowerment should be a distinct conceptual entity and should not be used interchangeably with other terms (Johnson, Rose, Dilworth, & Neilands, 2012; Fumagalli, Radaelli, Lettieri, Bertele, & Masella, 2015; Risling, Martinez, Young, & Thorp-Froslic, 2017). Fumagalli et al. (2015) reported that the unclear relationship between patient empowerment and other related terms (e.g. patient engagement and involvement) is one of the reasons for the lack of empowerment adoption. This section outlines the distinction between empowerment and other related terms.

The increasing encouragement of patients to play an active role in self-care and shared decisions has resulted in an explosion of terms such as “empowerment, engagement, enablement, participation, involvement and activation” (Fumagalli et al., 2015, p. 384). Empowerment is seen as a broader concept than the others (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016). In a systematic review on empowerment-related concepts from 1990 to 2013, Fumagalli et al. (2015) explained how empowerment and other related concepts are perceived and defined:

- Empowerment: in the literature, empowerment has been interpreted as a state of “being empowered”, a process of “empowering” patients or an “empowered” behaviour.

Accordingly, it was defined and seen as follows:

- Emergent state: it refers to “the ability of people to gain understanding and control over personal, social, economic and political forces in order to take action to improve their life situations” (Israel, Checkoway, Schulz, & Zimmerman, 1994, p. 152). The definition suggests that empowerment is the “possession of both *ability* ..... (a combination of knowledge and skills) and *motivation* (a combination of attitude and self-awareness)” (Fumagalli et al., 2015, p. 386). Being able and willing to play an active role in health treatment is necessary but not sufficient to develop ‘power’. Fumagalli et al. (2015) explained that “patients are in fact ‘empowered’ when they are ‘willing and able’ to restore a balance of ‘power’ with providers, but also when providers delegate responsibilities to patients” (p. 386).
- Process: empowerment has been additionally seen “as the process leading to personal transformation” (Fumagalli et al., 2015, p. 387). The focus here moves to the actions that improve the *ability* and *motivation* of patients (e.g. use of community coaches and education). This suggests that ability and motivation components do not emerge spontaneously, but from social activities that develop patients’ knowledge, skills and attitude.
- Behaviour: the acquisition of *ability* and *motivation* components (knowledge, skills, attitude and self-awareness) results in the actual behaviour change; and therefore, participation in self-management of the illness and involvement when making decisions related to condition.

In all previous three definitions of empowerment, the literature recommends caution in associating *empowerment* with *participation*. People who suffer from pain may not favour taking an active role in self-care, which needs to be understood. They prefer rather to be taken care of more than empowered, which should not be seen as a weakness but as a human state. Additionally, taking an active role in decision-making is not by itself an evidence of being empowered. Being *motivated* (having the attitude and self-awareness) without being *able* (knowledge and skills) might lead to negative results. On the other hand, when patients are *able*, but are not given the responsibility, that might make them frustrated. Therefore, the acquisition of both elements, as well as the consideration of patients' choices, are essential.

- **Patient Activation:** this refers to patients' ability and skills to "manage their condition, collaborate with their health providers, maintain their health functioning, and access appropriate and high-quality care" (Fumagalli et al., 2015, p. 388). Empowerment and activation share the same concept that patients should have the ability and motivation to manage their illnesses (Pekonen et al., 2020). However, whilst empowerment focuses on improving the whole lifestyle of patients in order to achieve better quality of life, activation is concentrated rather more on exact and particular enhancement objects of a particular illness. Therefore, empowerment is seen as having a larger connotation than activation. Fumagalli et al. (2015) explained that "the acquisition of ability and motivation does not involve exclusively a capacity to make decision on the specific diseases but in life as a whole" (p. 388).
- **Patient Enablement:** this focuses on providing patients with suitable skills and knowledge to make them able to understand their conditions and make decisions. It refers to the readiness

of patients to take an active role in making decisions or controlling one's health. Therefore, enablement is considered as a part of empowerment.

- **Patient Engagement:** this has two diverse interpretations. Engagement can be considered as a consequence of empowerment, when patients participate in self or shared management of the illness, or it can be seen as a cause of empowerment, when a patient behaves in a way that aims to improve their role in health care. Researchers have identified various activities that enable patient to be engaged in managing their health, such as making appointments, searching for suitable health care provider, staying informed about future treatment option and building a strong relationship with doctors (Gruman et al., 2010). Patient engagement was identified as a key enabler to effective interactive between patients and care providers (Tobiano et al., 2020). In conclusion, patients are seen as engaged when they deploy a strong *motivation* to become knowledgeable.
  
- **Patient Involvement/Participation:** the two terms have been interchangeably used to refer to the active role of patients in health treatments. However, Thompson (2007) distinguished the two terms as follows:
  - Involvement refers to the “degree to which patients take part in the decision-making process connoting a degree of transfer of power from the professional to the patient in the form of increased knowledge, control and responsibility” (p. 1308). Involvement differs when it is determined by patients rather than by doctors.
  - Participation can be seen as a part of involvement, which can be directed by both health care providers and their patients.

Thompson (2007) highlighted that there is no favoured kind of involvement. It should be driven by a patient's desire in specific situations. Patients therefore might express their empowerment by remaining detached from involvement.

Zimmerman's (1995) empowerment theory explains that empowerment operates at different levels including individual and organisational/ community levels. The theory describes that there are different processes that take place at each level and the organisational/ community empowerment is not the aggregation of the individual empowerment.

In conclusion, empowerment is seen in the literature as an emergent state, process and behaviour that holds implicitly various related concepts. This section has discussed the differences between the term empowerment and other similar terms and provided an overview of measurements used to evaluate empowerment. The next section will highlight the meaning of empowerment in diabetes care.

### ***2.7.3 Empowerment in Diabetes Care***

In terms of diabetes care, Anderson and Funnell (2010) explained that the purpose of diabetes education is not about convincing patients to follow doctors' instructions, but it is about increasing patients' independence. They added that empowerment for T2D patients presents them with an opportunity for making sensible and achievable goals. The authors noted that empowerment is specifically needed for T2D patients since the advised alterations are strongly related to patients' lifestyle, and there is a shortage of information provided to diabetes patients when formally diagnosed (Beeney et al., 1996; Duggan & Bates, 2008; Zhang, 2017). Lambrinou et al. (2019) Funnell et al. (1991) agreed that empowerment is particularly important to diabetes since its concepts are fundamentals for diabetes education. Scholars have defined basic concepts of empowerment in the domain of diabetes care, which will be discussed in the next section.

The key elements of empowerment are founded on the belief that positive health outputs can be achieved when a partnership is made between both patients and health care providers (Coulter & Collins, 2011). Funnell and Anderson (2000) explained that there are two main steps in the process of empowerment in diabetes. First, roles and responsibilities need to be redefined to match the reality of diabetes care. The traditional view of provider-centred care must be changed to involve patients as the primary decision-maker. When doctors want patients to behave in a way that doctors want, they will both be frustrated. However, when doctors recognise that the care should be patient-directed, they become more effective practitioners. Second, relationships that promote collaboration and partnership between patients and doctors must be created. As a result of the first step, the relationship between patients and care providers has changed to contain mutual expertise and responsibility from both sides. An effective plan that helps patients to achieve their goals can be created once doctors recognise that patients are expert on their own lives which can benefit from when designing health plans. When doctors actively support patients to achieve their own goals, patients become more committed and self-motivated which results in eliminating the problem of noncompliance and reaching positive health outcomes (Anderson, 1995). Funnell et al. (1991) contrasted the traditional and the empowering models for diabetes care (Table 2.1).

**Table 2.1 Comparison of Traditional and Empowering Diabetes Educational Models**

<b>Traditional Medical Model</b>	<b>Empowering Person-Centred Model</b>
Diabetes is a physical illness	Diabetes is a biopsychosocial illness.
Relationship of provider and patient is authoritarian based on provider expertise.	Relationship of provider and patient is democratic and based on shared expertise.
Problem and learning needs are usually identified by professional.	Problem and learning needs are usually identified by patient.
Professional is viewed as problem solver and caregiver, i.e., professional responsible for diagnosis, treatment and outcome.	Patient is viewed as problem solver and caregiver, i.e., professional acts as a resource and both share responsibility for treatment and outcome.
Goals is compliance with recommendations. Behavioural strategies are used to increase compliance with recommended treatment. A lack of compliance is viewed as a failure of patient and provider.	Goals is to enable patients to make informed choices. Behavioural strategies are used to help patients change behaviours of their choosing. A lack of goal achievement is viewed as feedback and used to modify goals and strategies.
Behaviour changes are externally motivated.	Behaviour changes are internally motivated.
Patient is powerless, professional is powerful.	Patient and professional are powerful.

**Data Source: Adapted from Funnell et al. (1991)**

As shown in Table 2.1, the traditional model is driven by doctors as the key players in the care process. Its goal is to convince patients to comply with doctors' treatment recommendations to improve patients' physical status. According to Funnell et al. (1991), this model views patient education as "a process designed to influence the knowledge, attitudes, and behaviour of patients to enhance their compliance with the treatment recommendations in order to improve their glycemetic control" (p. 38). Naik et al. (2011) reported that diabetes patients who follow the traditional model have clinically insignificant improvements. However, in the patient-directed approach, patients are seen as the main motivators and doctors as supporters and a source of information. The goal of this model is to improve the quality of life of patients by enabling them take responsibility for their own

health via recognition and promotion of individual strengths, informed choices and personal goals (Funnell et al., 1991). Zoffmann and Kirkevold (2012) reported remarkable improvements for diabetes patients who follow the empowerment model. Based on this vision, Anderson and Funnell (2010) developed foundational empowerment principles for diabetes care (as shown in Table 2.2). The principles show that health care professionals (HCPs) are responsible for ensuring that their patients are equipped to make informed decisions and understand their consequences.

**Table 2.2 Fundamental Principles of Diabetes Empowerment.**

<b>Fundamental Principles of Empowerment</b>
1- Patients provide 98% of their own diabetes care.
2- The greatest impact on the patient's health and well-being is a result of their self-management decisions/actions during the routine conduct of their daily life.
3- Diabetes is so woven into the fabric of the patient's life that many, if not most, of the routines of daily living affect and are affected by diabetes and its self-management.
4- Because patients are in control of their daily self-management decisions, they are responsible for those decisions and the resulting consequences.
5- Patients cannot surrender the control or responsibility they have for their diabetes self-management no matter how much they wish to do so. Even if patients turn their self-management completely over to a HCP, they can change their mind about that decision at any time. Thus, they remain in control at all times.
6- Health care professionals cannot control and therefore cannot be responsible for the self-care decisions of their patients.
7- HCPs are responsible for doing all they can to ensure their patients are making informed self-management decisions, i.e., informed by an adequate understanding of diabetes self-management and an awareness of the aspects of their personal lives that influence their self-management decisions.

**Data Source: Adapted from Anderson and Funnell (2011)**



Applying HCPs recommended behaviour changes is difficult, or impossible in some cases, for many diabetes patients (Anderson & Funnell, 2010). As a result, HCPs frequently feel disappointed at their futile efforts and they accuse patients of not achieving the advised results. On the other hand, patients also become frustrated since they are unable to apply the recommended behaviour change and mostly feel blamed by their doctors and feel labelled as being non-compliant (Hoover, 1980; Weiss, 2006). Therefore, a patient-focused way of managing diabetes patients is essential to accomplish the wanted results. The principles identified above are built in this way, which requires the competence of HCPs, as well as the knowledge and preferences of patients about their priorities, goals, values, concerns, traditions, resources and culture in order to reach effective diabetes self-management plans and outcomes. Anderson and Funnell (2010) emphasised that the need for two different types of expertise requires an effective collaboration between HCPs and patients to form programmes that meet patients' diabetes needs and their lifestyle.

The main principles of empowerment were discussed in this section. The next section will discuss the relationship between patients and care providers as it is a key element in facilitating empowerment.

#### ***2.7.4 Doctor-patient relationship***

##### ***2.7.4.1 Introduction***

The doctor-patient relationship is a critical component of the care service (Harbishettar et al., 2019) and its quality was reported to be “the decisive factor for the success of treatment” (Fritzsche et al., 2020, p. 25). The quality of the relationship has been found to affect patient empowerment (Ippolito et al., 2019). Therefore, this section first describes the main types of the relationship and it then explores the role of trust in the relationship.

### 2.7.4.2 Types of relationship

Historically, the relationship started with care providers having full control of the relationship (i.e. a paternalistic relationship where care providers were active and patients were passive) and this was explained by the limited number of care providers, mostly belonging to the upper class (Hellin, 2002). However, this relationship has been criticised and various scholars argued that providing patients with more than one type of relationship including a democratic relationship has the potential to contribute to better health outcomes (Fritzsche et al., 2020; Mead & Bower, 2000). They explained that the right type of relationship should be chosen based on the personality and preference of both patients and doctors, as well as on the nature of the condition (Fritzsche et al., 2020). Various researchers outlined different types of relationships. Mohanty (2017), for example, reported four types of the relationship and each type has a different power level as Table 2.3 below explains.

<b>Patient control</b>	<b>Doctor control</b>	
	<b>Low</b>	<b>High</b>
<b>Low</b>	Default	Paternalism
<b>High</b>	Consumerist	Mutuality

**Table 2.3 Types of doctor-patient relationship as reported by Mohanty (2017)**

In the paternalistic relationship, doctors act as a parent who knows what is appropriate for the patient and decides on his/her behalf. This relationship is preferred by some patients since they can rely fully on the care provider without the need to worry about the consequences of making health-related decisions themselves. The mutuality relationship represents an equal-involvement relationship in which both sides of the relationship are seen as experts (i.e. doctors bring their medical knowledge and experience and patients bring their practical experience, knowledge and preferences). In the consumerist relationship, doctors act as service providers who accede to the demands of the patient (i.e., the customer in this situation). Finally, Mohanty (2017) explained the a default relationship is

characterised by a low involvement of both sides of the relationship. Doctors in this relationship lack sufficient direction and patients are used to be passive in their relationships with care providers.

Other researchers have reported similar types of relationships. Fritzsche et al. (2020), for instance, explained three types of doctor-patient relationships: paternalistic relationship, consumer-provider relationship and partnership. Other scholars categorised patients into different models of engagement in decision making. For example, Charles et al. (1997; 1999) grouped the patients into three models: paternalistic, informed and shared models. While the paternalistic model is similar to the paternalism relationship outlined above, the shared and informed models can be seen as similar to the mutuality and consumerist relationships respectively. Charles et al. (1997) noted that to implement successful shared decision-making, both doctor and patient have to be involved in the relationship, exchange information, discuss preferred treatments and agree on the preferred treatment.

#### ***2.7.4.3 Trust in doctor-patient relationship***

Trust in the doctor-patient relationship is a crucial component of patient care. A trusting relationship was reported to increase the adherence to treatment and decrease relapse (Birkhäuser et al., 2017; Harbishettar et al., 2019) and health care costs (Gopichandran, 2019). Trust has many definitions that focus on various aspects. For example, trust can be defined as “an unwritten agreement between two or more parties for each party to perform a set of agreed-upon activities without fear of change from any party” (Shore, 2003, p. 13). It is based on the belief that both parties of the relationship will act in their common interest and will not attempt to harm the other side of the relationship (Gilson, 2003; Morgan & Hunt, 1994). Anderson and Dedrick (1990) defined trust in the doctor-patient relationship as a combination of expectations that patients have towards their doctors. It is built on the confidence and reassurance in care providers (Caterinicchio, 1979) and that they will do the best for the patient by recognising their vulnerability (Turabian, 2019). Trust in the health care context has been

summarised as having two main levels: (1) micro-level: operating between the patient and doctor; and (2) macro-level: occurring between patients, the public and the health care system (Rasiah et al., 2020). The concept of trust in the health care is, however, interpreted differently by people. Some individuals think that trust in doctors means absolute surrender to their judgement and decisions because they know best (Charles et al., 1997). This is clear in some relationships, where doctors have high or full power in the relationship such as the paternalism relationship discussed above.

Recently, various social, political and technical changes have influenced the nature of patients' trust in health care providers and the health care system (Blendon et al., 2014; Donaldson et al., 2000). The emergence of the Internet, for example, has provided much greater information resources that contributed to enhancing the knowledge of patients (Finney Rutten et al., 2015; Lyu et al., 2016; Sechrest, 2010). As a result, this has increased their engagement with their care and empowerment status, which has negatively affected the nature of trust in doctors (Blendon et al., 2014). Other scholars, however, reported the opposite results, suggesting that online health information seeking for patients was found to strengthen their trust in care providers (Finney Rutten et al., 2015; Minsun et al., 2006). These contradictory findings were explained by Lyu et al., (2016) who reported that online health information seeking might harm the relationship, if the information found online is asymmetric to the information provided by the care provider. Trust involves reciprocity, meaning that if one side of the relationship (e.g., the doctor) trusts the other side (e.g., the patient), the latter would report a similar level of trust (Petrocchi et al., 2019). Other factors that influenced trust in this relationship included good agreement between the two parties (Banerjee & Sanyal, 2012), communication behaviour of doctors (Chandra et al., 2020), expectations and previous experiences with the health care system (Isangula, 2018) and respect for the doctor and assurance of treatment (Gopichandran & Chetlapalli, 2015).

To summarise, several types of patient-doctor relationship and the role of trust in the relationship were discussed in this section. The next section will review related studies that investigated the role of OSGs in empowering patients.

### 2.7.5 Existing Research on Patient Empowerment in OSGs

Table 2.4 below summarises most relevant studies that were published prior conducting the present study. The studies mainly identified empowering and disempowering processes found in the OSGs. Further discussion is presented in Section 2.8.

**Table 2.4 Summary of literature related to the use of online support groups as an empowerment tool for patients**

Study Title and Authors	Purpose	Method	Main Findings
<p>Empowering Processes and Outcomes of Participation in Online Support Groups for Patients with Breast Cancer, Arthritis, or Fibromyalgia.</p> <p>By: Van Uden-Kraan et al. (2008).</p>	<p>To investigate if patients experience empowerment by taking part in OSGs.</p>	<p>Qualitative.</p>	<ul style="list-style-type: none"> <li>• The following empowering processes were found: “exchanging information, encountering emotional support, finding recognition, sharing experiences, helping others and amusement” (p. 405).</li> <li>• Disempowerment processes: “being unsure about the quality of the information, being confronted with negative sides of the disease and being confronted with complainers” (p. 405).</li> <li>• Disempowering processes were discussed less frequently.</li> <li>• Reported empowering outcomes were: “being better informed; feeling confident in the relationship with their physician, their treatment, and their social environment; improved acceptance of the disease; increased optimism and control; enhanced self-esteem and social well-being; and collective action” (p. 405).</li> </ul>
		<p>Quantitative.</p>	<ul style="list-style-type: none"> <li>• This quantitative study confirmed the findings of the previous qualitative study. Users experienced empowerment through the use of OSGs.</li> </ul>

Participation in Online Patient Support Groups Endorses Patients' Empowerment.

To explore if patients feel empowered by participation in OSGs.

- No significant differences between different patient groups were observed.

By:

Van Uden-Kraan, Drossaert, Taal, Seydel and van de Laar (2009).

An Investigation into the Empowerment Effects of Using Online Support Groups and How This Affects Health Professional/Patient Communication.

To investigate the potential of OSGs to foster empowerment and how it affects the patient/health professional relationship.

Quantitative.

- All empowerment processes and outcomes in the previous two studies were found to be present in this study too.
- The authors concluded that OSGs can offer empowerment for their users.

By:

Bartlett and Coulson (2011).

Empowerment of Patients in Online Discussions About Medicine Use.

By:

Van Berkel, Lambooi and Hegger (2015).

To investigate the relationship between medicine use and patient empowerment.

Qualitative.

- All empowerment processes that were identified in the previous three studies were reported to occur in this study too.
- Different conditions varied in the number of empowerment processes.
- Information shared in these processes help patients to use medicine more effectively.
- The posts showed that patients still see doctors as a primary source in treating the illness.

Fostering Empowerment in Online Support Groups.

By:

Barak et al. (2008).

To identify disinhibition effects in OSGs and processes, advantages and disadvantages from participating.

Literature review of related studies.

- It concluded that OSGs are designed to assist patients to take care of themselves and be independent.

Are online support groups always beneficial? A qualitative exploration of the empowering and disempowering processes of participation within

To explore whether the empowerment signs mentioned by Van Uden-Kraan et al. (2008) occur in

Qualitative.

- The researchers reported consistent empowerment and disempowerment processes and outcomes with Van Uden-Kraan et al. (2008).
- The following empowerment processes were reported: “exchanging information, sharing experiences, connecting to others, encountering emotional support, finding recognition and understanding and helping others” (p. 983).



<p>HIV/AIDS-related online support groups.</p>	<p>HIV/AIDS OSGs or not.</p>	<ul style="list-style-type: none"> <li>• Disempowerment processes: “being unable to connect physically, inappropriate behaviour online, declining real life relationships, and information overload and misinformation; and empowering outcomes: increased optimism, emotional well-being, social well-being, being better informed, improved disease management and feeling confident in the relationship with physicians” (p. 983).</li> </ul>
<p>By: Mo and Coulson (2014).</p>		
<p>Narratives of Empowerment and Compliance: Studies of Communication in Online Patient Support Groups.</p>	<p>To investigate if communication in OSGs is a source of empowerment or to be perceived as a form communication that aims to assist patients to follow their doctors' instructions.</p>	<p>Qualitative.</p> <ul style="list-style-type: none"> <li>• The study confirmed the effectiveness of OSGs for individual empowerment, for collective group identity, but not for collective empowerment.</li> <li>• On a collective level, the OSG is empowering the users to follow doctor’s advice as a group.</li> </ul>
<p>By: Wentzer and Bygholm (2013).</p>		
<p>The Effect of Computer-Mediated Social Support in Online Communities on Patient Empowerment and Doctor–Patient Communication</p>	<p>To examine how people with diabetes in Korea exchange computer-mediated social support (CMSS) in diabetes OSGs and how this affect their empowerment and</p>	<p>Quantitative.</p> <ul style="list-style-type: none"> <li>• The authors reported significant relationships among users’ OSGs activities, perceived CMSS, feeling of empowerment and their aim to efficiently interact with the doctor.</li> <li>• Patients who participated more in OSGs found to perceive greater CMSS from other members in the group.</li> <li>• Perceived CMSS significantly predicted patients’ intention to be active when communicating with doctors through empowerment.</li> </ul>
<p>By:</p>		

Oh and Lee (2012)

interaction with the care providers.

- Empowerment found to be a valid fundamental mechanism that explains how the perceived CMSS influences the intention of patients to be active when communicating with doctors.

Empowering processes in online support groups among people living with HIV/AIDS: A comparative analysis of 'lurkers' and 'posters'

To test if Van Uden-Kraan et al.'s (2008) empowerment processes occur for non-active users (lurkers) of OSGs.

Quantitative.

- Non-active users (lurkers) of OSGs may be as empowering as those who are active.

By:

Mo and Coulson (2010)

The effect of an online support group on patients treatment decisions for localised prostate cancer: An online survey.

To investigate the effect of an OSG on the final treatment decision for localised prostate cancer

Quantitative.

- Nearly 30% of patients in the study revised their initial treatment plans after participating in an OSG.
- OSGs have potential in making positive impacts on patients.

By:

Huber et al. (2017)

Recently, more studies have been published to understand the role of OSGs on patient empowerment. Table 2.5 below summarises most relevant studies that were published after conducting the present study.

**Table 2.5 Summary of recent literature related to the use of online support groups as an empowerment tool for patients that were published after conducting the present study**

Study Title and Authors	Purpose	Method	Main Findings
<p>Participation of Patients with Type 2 Diabetes in Online Support Groups is Correlated to Lower Levels of Diabetes Self-Management. By: Herrero et al. (2020)</p>	<p>Whether or not being part of OSG is associated to a better management of the condition for people with Type 1 and 2 diabetes.</p>	<p>Quantitative</p>	<ul style="list-style-type: none"> <li>• Being part of OSGs was linked to decreased self-management and health complications for people with T2D but not for these with T1D.</li> </ul>
<p>Online peer-to-peer support for persons affected by prostate cancer: a systematic review. By: Ihrig et al. (2020)</p>	<p>To investigate the influence of OSGs on people with prostate cancer.</p>	<p>Qualitative</p>	<ul style="list-style-type: none"> <li>• OSGs were key source of information and emotion support for various people with prostate cancer that influenced their treatment decision making.</li> <li>• A limited synthesis was observed in the literature. This suggests the need for more research in the area.</li> </ul>
<p>Lurking towards empowerment: Explaining propensity to engage with online health support groups and its association with positive outcomes. By: Fullwood et al. (2019)</p>	<p>To understand the engagement behaviour and empowering impacts of OSGs on lurking users.</p>	<p>Quantitative</p>	<ul style="list-style-type: none"> <li>• The study outlined nine reasons that contributed to less engagement/ lurking in OSGs including poor sense of community, fulfilling the need without the necessity to post and lack of time.</li> </ul>

<p>Do online health communities enhance patient–physician relationship? An assessment of the impact of social support and patient empowerment.</p> <p>By: Audrain-Pontevia and Menvielle (2018)</p>	<p>To investigate the effect of OSGs on doctor-patient relationship and patient empowerment.</p>	<p>Quantitative</p>	<ul style="list-style-type: none"> <li>• The reasons for lurking were found to be predictive to the benefits they receive from using OSGs.</li> <li>• The use of OSGs was positively associated with better participation in doctor visits and patient empowerment which determines the commitment of patients to the doctor-patient relationship.</li> <li>• Surprisingly, patients’ commitment to the relationship was negatively significant associated with their empowerment level.</li> </ul>
<p>State of the science: a scoping review and gap analysis of diabetes online communities.</p> <p>By: Litchman et al. (2019)</p>	<p>To identify what is known about the benefits and consequences of using diabetes online communities (including but not limited to OSGs).</p>	<p>Scoping review</p>	<ul style="list-style-type: none"> <li>• Diabetes online communities were found beneficial to their users with minimal disadvantages found.</li> <li>• The benefits of using the communities were mainly related to “clinical, behavioural, psychosocial and community outcomes” and the potential consequences were “quality of information, risky behaviour exploration, acute concerns, psychosocial, privacy, and inactivity” (p. 466).</li> <li>• The review reported a lack of research in the area of diabetes online communities.</li> </ul>

<p>Role of empowerment and sense of community on online social health support group.</p> <p>By: Sharma and Khadka (2019)</p>	<p>To explore the reasons for users to continue using OSGs to manage their long-term conditions.</p>	<p>Quantitative</p>	<ul style="list-style-type: none"> <li>• Information support was found to be the dominant reason for users to continue using OSGs.</li> <li>• Patient empowerment and sense of community were positively associated with the continuous use of OSGs.</li> </ul>
<p>Exploring motivations for using online patients community and its effects on patients' health outcomes.</p> <p>By: Xu and Liu (2019)</p>	<p>To investigate the motivation and health outcomes for using OSGs.</p>	<p>Quantitative</p>	<ul style="list-style-type: none"> <li>• Utilitarian, social and technology gratifications were found to be key in determining patients use to OSGs.</li> <li>• The use of OSGs was linked to enhanced empowerment and health literacy.</li> </ul>
<p>Using online support communities for Tourette Syndrome and Tic disorders: online survey of users' experiences.</p> <p>By: Perkins et al. (2020)</p>	<p>To investigate the users' experience of engaging in Tourette Syndrome and Tic disorders OSGs.</p>	<p>Quantitative</p>	<ul style="list-style-type: none"> <li>• OSGs were mainly used to compensate the absence of face-to-face support.</li> <li>• OSGs were found to be valuable source to fulfil the informational and emotional needs of their users. Other benefits of using OSGs included breaking the isolation of users and enhancing their psychological well-being.</li> </ul>

Table 2.5 shows that the use of OSGs by patients is a growing research area that attracted the attention of many scholars. Although there were some studies on diabetes, they were mostly quantitative in nature and did not clearly explain how the use of OSGs influenced their users. They also acknowledged the need for in-depth qualitative research to understand the effect of OSGs on their members (e.g. Herrero et al. (2020) and Litchman et al. (2019)). In particular, the literature published recently did not fulfil the gap related to identifying how the use of OSGs affected the empowerment status of their users, how the information exchanged in the groups is utilised by the users and how environmental factors, such as the health care system and its policy, influence the use of the OSGs and their empowerment in general. The present study aimed to fulfil this gap as the next sections explain.

## 2.8 Synthesis

The literature firstly demonstrates the importance of empowerment in improving health outcomes, especially for those with chronic illnesses such as diabetes. People with T2D must make a number of daily decisions regarding their health, including blood glucose monitoring, stress management, physical activity, nutrition and medication. Additionally, they need to communicate with doctors, relatives, friends and co-workers to achieve the necessary level of support to manage the illness. The difficulty of the disease demands patients and doctors to work collectively to achieve better results. The patient's environment, lifestyle and preferences must be considered by doctors to define and achieve reasonable goals. To achieve such a relationship, patients need to be well informed, effectively engaged and highly committed.

Secondly, the literature shows the movement towards adopting empowerment in health care systems by many health organisations worldwide. In particular, the NHS has launched several initiatives that aim to involve people in their own care and make them empowered (Jones, 2015), and planned to achieve patient-centred care approach by 2020 (NHS England, 2014b). The movement comes after realising that people with chronic illnesses spend less than 1% of their time in contacting their care providers (NHS England, 2014b) and account for the majority of health care appointments and spending. Involving them and establishing a partnership relationship between patients and care providers is therefore seen as essential.

Thirdly, the literature shows that OSGs have been widely used by people with various illnesses as a mean of information source and social support. This use has positive and negative implications on the management of the illness, the relationship between patients and care providers, patients' lifestyle, feelings and emotions. Therefore, it can result in both

improving or worsening patient empowerment and overall quality of life. Many studies have been undertaken to understand the effects of this use on patient empowerment; however, they focused mainly on one aspect of empowerment, such as the patient-doctor relationship (Van Uden-Kraan et al., 2008). Other studies have analysed processes that occur on OSGs and labelled the positive ones as empowering and the negative ones as disempowering (e.g. sharing information is empowering and sharing negative experiences is disempowering) without investigating whether the “empowering processes” truly results in empowering outcomes (e.g. whether and how the shared information resulted in understanding the illness or making the patient confused, depressed and dissatisfied with the care provider). In addition, empowerment was an ambiguous concept in most studies that examined OSGs. Its main constructs were not clearly identified and it has been interchangeably used with other terms (such as patient activation and patient involvement). As a result, it was not clear how empowerment was measured. The unclear definition of empowerment and its main constructs results in a lack of empowerment adoption (Fumagalli et al., 2015). It is thus difficult to claim that previous studies, which had no clear definition of empowerment, its constructs and measurement, have truly measured empowerment or other related phenomena.

## **2.9 Gaps in the literature**

Reviewing the literature has shown that OSGs are promising media for facilitating information sharing and social support for people with T2D. Whilst there are a large number of studies on the implications of using OSGs for many illnesses, there is relatively little research on the role of OSGs for people with diabetes. The relationship between people with T2D using OSGs and empowerment elements has not been explored. Furthermore, previous studies have not clearly used specialised empowerment frameworks to investigate such use. To the best of the researcher’s knowledge, the HCE model has not been used to investigate



how OSGs affects patient empowerment. The researcher used the HCE model as a guide in the design and analysis of the qualitative data generated in this study. Specifically, he examined how different contextual and intrapersonal factors and personal resources influence different empowerment elements. Posts from OSGs were purposively selected to look at the different factors and resources that were emphasised by the model. For instance, a thread where an OSG user expresses his/her opinion about the quality of the health care facility in his/her area and how that influenced the management of his/her diabetes was considered. Such a thread might contain various posts from different users with their experiences with their local health care providers and how that influenced the management of their diabetes. In the HCE model, “provider factors” are one of the contextual factors that might influence patient empowerment and sampling such a thread helped in providing a deeper understanding about how this factor influence patient empowerment (as explained in Section 2.3.4.4). Similarly, threads that contain expression of emotions (such as hope, anxiety and depression) might show how these intrapersonal factors influence patient empowerment and the use of the personal resources (e.g. social support). Likewise, in conducting and analysing the interviews, the different cultural backgrounds, education levels, age groups and geographical locations were examined to understand how different contextual factors influence the use of personal resource and the management of the intrapersonal factors, and as a result their health care empowerment. Applying the HCE model provided a greater understanding on how empowerment elements are influenced by the use of OSGs for people with T2D. This provided deeper insights on the online information seeking behaviour of people with T2D. The aim of the current research was to fill this gap by undertaking an in-depth, multi-method study.

## **2.10 Research Questions**

Giving the above, the aim of the research was to answer the following overarching research question:

- How can OSGs influence patient empowerment for people with Type 2 diabetes?

Further research questions arising as a result of that are:

- What are the information needs and behaviours of people with Type 2 diabetes using OSGs?
- How do patients with Type 2 diabetes utilise the information they receive on OSGs and how does this influence their health behaviours?
- How do the various contextual and intrapersonal factors and personal resources influence patient empowerment for people with Type 2 diabetes?

## **2.11 Conclusion**

In conclusion, empowerment has the potential to facilitate patient control through self-management and shared decision making, along with collaborative, equitable and cost-effective approaches to health care. People with T2D are highly in need to be empowered since they control the majority of their illness; and understanding the role of OSGs in facilitating empowerment for people with T2D is an area in which there is a need for research. The literature has emphasised the importance of OSGs in fostering empowerment for people with chronic diseases, this study therefore aims to answer the questions in Section 2.10. The next chapter will explain the methodology that was adopted and used to answer the identified questions.

## **CHAPTER 3 : METHODOLOGY**

### **3.1 Introduction**

The previous chapter examined existing literature on diabetes and the use of online health forums, and identified gaps in the literature, and finally identifying the research questions (Section 2.10). This chapter will explain the research philosophy and techniques that were adopted in the study and the reasoning behind selecting them. It will start by outlining the research paradigm (Section 3.2), methodology (Section 3.3), methods (Section 3.4), tools that will be employed to answer the identified research questions (Section 3.5) as well as other ethical (Section 3.9) and quality (Section 3.10) issues. Separate sections in Chapter 4 and 5 will explain how these methodological steps were undertaken in each study.

### **3.2 Research Paradigm**

According to Bryman (2003), a research paradigm is “a cluster of beliefs and dictates which for scientists in a particular discipline influence what should be studied, how research should be done, how results should be interpreted, and so on” (p. 4). Research paradigm is sometimes also called *worldview* (Creswell, 2009) or *broadly conceived research methodologies* (Neuman, 2002). It refers to the common beliefs and arguments among scientists in a given discipline about how a problem should be understood and solved (Kuhn, 1970). The research paradigm is usually defined by the researcher’s area of study (Creswell, 2009). This section will explain the research paradigm adopted in the current study and the implications for this adoption on the research.

The current study adopts the pragmatic paradigm, which comes from “actions, situations and consequences rather than antecedent conditions” (Creswell, 2009, p. 28). In the pragmatic paradigm, rather than concentrating on techniques, researchers highlight the study problem

and use all ways possible to solve it (Creswell, 2009; Rossman & Wilson, 1985). It gives researchers the freedom to choose appropriate methods that fit the subject under examination without limiting them to any one system of philosophy (Denscombe, 2008). Instead of searching for metaphysical truths, pragmatic researchers consider “what works” to be the truth (Tashakkori & Teddlie, 1998). Howe (1988) summarised this direction as follows:

After all, much of pragmatic philosophy (e.g. Davidson, 1973; Rorty, 1982; Wittgenstein, 1958) is *deconstructive*—an attempt to get philosophers to stop taking concepts such as “truth”, “reality”, and “conceptual scheme” turning them into superconcepts such as “Truth”, “Reality”, and “Conceptual Scheme” and generating insoluble pseudoproblems in the process. (p. 15)

Tashakkori and Teddlie (1998), Patton (1990) and Morgan (2007) emphasised the importance of focusing the attention of social science research on the research problem and using pluralistic approaches to derive knowledge about the problem. According to Howe's (1988) concept of pragmatism, the paradigm indicates that both quantitative and qualitative methods are compatible; therefore, researchers could make use of both methods in their study to understand the problem under investigation. Brewer and Hunter (1989) supported this point:

However, the pragmatism of employing multiple research methods to study the same general problem by posing different specific questions has some pragmatic implications for social theory. Rather than being wed to a particular theoretical style . . . and its most compatible method, one might instead combine methods that would encourage or even require integration of different theoretical perspectives to interpret the data. (p. 74)

Creswell (2009) summarised pragmatism's philosophical basis for research as follows:

- Pragmatism is not committed to any one system of philosophy.
- Researchers can adapt any approach to answer the research question and meet the objective of their study.
- The world is not seen as an absolute unity by pragmatist researchers. Similarly, mixed-method researchers look at multiple approaches for collecting and analysing data instead of using only one approach (either quantitative or qualitative).
- Researchers in this paradigm focus on what and how to study according to the expected outcomes and desired direction.
- Studies in this paradigm take place in multi settings, including surrounding factors.

The pragmatic paradigm was therefore adopted in the present research since it gives the researcher the option to apply various techniques, different types of data collection and analysis, different worldviews and different assumptions. This research adopted a multi-method approach, in which the first phase involved collecting posts from OSGs and analysing them qualitatively. In the second phase, the researcher interviewed people with T2D who are current or former OSG users. Thus, pragmatism is seen as an ideal paradigm for the current study since it puts the attention on the research questions and allows the researcher to employ any suitable approach that is helpful in answering the questions.

Ontology and epistemology are two other ways of defining the philosophy of the research. Ontology deals with researchers' beliefs about the nature of reality (Saunders, Lewis, & Thornhill, 2009) and asks questions such as: “what is the form and nature of reality?”, “what is there that can be known about it?” and “how things really work?” (Guba & Lincoln, 1994, p. 108). On the other hand, epistemology is about the researcher’s perspective on what forms satisfactory knowledge (Saunders et al., 2009). It deals with questions like "What is knowledge? Can we have it? How do we know things and justify our beliefs? What are the

kinds of things we know?" (Moreland & Craig, 2003, p. 14). In the pragmatic paradigm, researchers adopt from a wide range of research designs and strategies (e.g. different ontologies and epistemologies) based on the problem they are investigating (Saunders et al., 2009). Therefore, the most important determinants of the ontology and epistemology of pragmatist research are the research problem and the research questions.

Regarding ontological view in relation to this study, the researcher believes that there is no single 'truth' about empowerment, rather there are many views and dimensions where people with T2D can feel empowered or disempowered. Nevertheless, the focus of the research is not on the truth of empowerment, but on the impact of the use of OSGs on the previously identified elements of empowerment (e.g. engagement, involvement, etc.). The researcher believes that these elements are present in patients' daily activity and can have major practical influences on people's life.

In terms of epistemological position, the current research adopts the subjectivist view, which follows the interpretivist position. The pragmatic philosophy suggests that the research epistemology should be directed by the research questions (Saunders et al., 2009).

Interpretivism considers people, their views and beliefs as the main source of data (Mason, 2002). Blaikie (2000) explained this:

Interpretivists are concerned with understanding the social world people have produced and which they reproduce through their continuing activities. This everyday reality consists of the meanings and interpretations given by the social actors to their actions, other people's actions, social situations, and natural and humanly created objects. In short, in order to negotiate their way around their world and make sense of it, social actors have to interpret their

activities together, and it is these meanings, embedded in language, that constitute their social reality. (p. 115)

The object of the current research is not to test a hypothesis, but to understand or develop a theory. Therefore, an interpretivist approach was seen as the most appropriate epistemological position for the present study.

### **3.3 Research Methodology and Time Horizon**

This was a multi-method, cross-sectional, exploratory study. The researcher first collected and analysed posts from selected diabetes OSGs. Then, he conducted interviews with current or former OSGs users. The collected data were analysed by the researcher using a qualitative thematic analysis. Even though some descriptive statistics might have been obtained to provide additional information (e.g. participants' demographics, most frequent words in online posts), the study was best suited for qualitative methods. As Mason (2002) explained, "qualitative research often does use some form of quantification, but statistical forms of analysis are not seen as central" (p. 4).

Cross-sectional studies are conducted at a single moment in time (Levin, 2006). In contrast, in longitudinal research studies, data are collected repeatedly with the same sample of participants over a period of time. Both cross-sectional and longitudinal studies are observational, which means that investigators collect data about the subject under investigation without manipulating the study environment (Mason, 2002). It was difficult for the current study to be longitudinal, both from an ethical and a practical point of view.

Tracking online users' posts over a long period of time would require their consent and, in addition, it could pose the potential risk of identifying them as their posts would be collected

over time and put together to be analysed. The University of Sheffield's (n.d.) ethic policy explained: “the potential of social media research to draw attention to posts and/or individuals that may otherwise have been lost in a crowd should be considered in relation to how such attention may risk harm” (p. 63). From a practical perspective, participating in OSGs might require some time to impact on participants’ life. It would therefore have been difficult to interview participants before and after their use of OSGs within the timeframe of the PhD study. Therefore, this study adopted a cross-sectional observational approach.

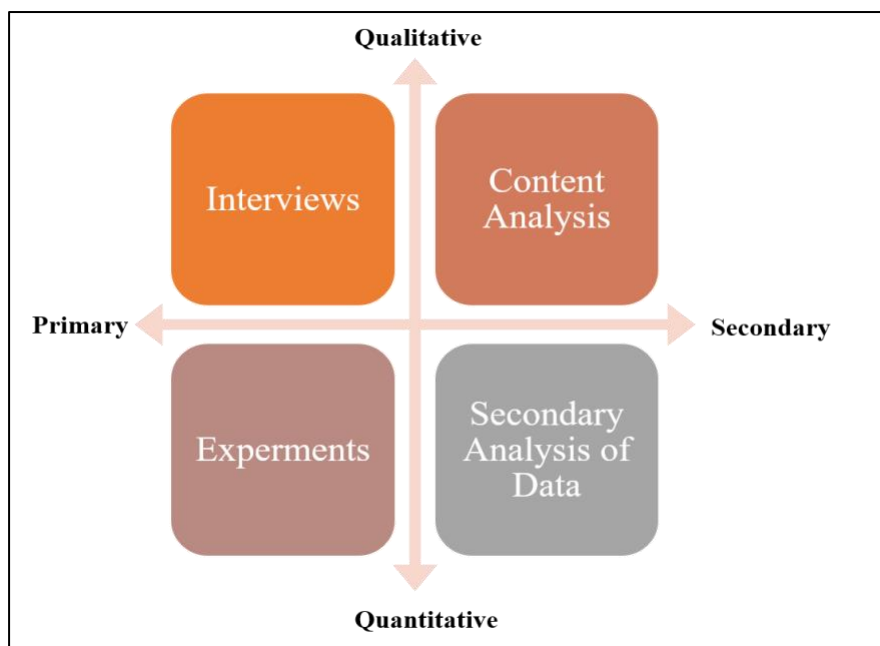
Lastly, exploratory studies intend to know what is occurring and explore new perceptions about a phenomena (Robson, 2002). They explore the research questions with varying levels of depth and do not aim to provide a final answer to the questions. They are flexible and adaptable to changes, therefore, the direction of an exploratory study can change when a new data and insights appear (Saunders et al., 2009). Creswell (2009) suggested that qualitative studies tend to be exploratory. This study explored the effects of using OSGs on people with T2D to provide a deep understanding about the current situation.

### **3.4 Research Method**

The present study applied two methods to answer the research questions: online text analysis and semi-structured interviews. First, posts from diabetes OSGs were collected and analysed using thematic analysis to explore situations in which OSGs have implications on peoples’ lives. It was expected that many OSG users might have not shared the implications of using OSGs directly; therefore, the researcher looked for any indication of empowerment/disempowerment arising from the use of OSGs, both explicit and implicit. This research method was chosen to help the researcher understand what processes take place in OSGs and how these processes influence online users. In addition, the analysis of online



posts helped the researcher in designing and conducting the interviews. As Merriam (1988) explained, “documents of all types can help the researcher uncover meaning, develop understanding, and discover insights relevant to the research problem” (p. 118). Document analysis is mostly used in combination with other qualitative methods as a means of triangulation (Bowen, 2009) (Figure 3.1). In the present study, text analysis, from OSGs, was carried out which can be seen similar to document analysis.



**Figure 3.1 A two-dimensional model of research methods. Data Source: Adapted from Trochim et al. (2015)**

Figure 3.1 above shows the two main dimensions of research methods: the types and sources of data. The first dimension refers to the type of the data whether it is quantitative or qualitative. The second dimension indicates the source of the data; this is primary, if the researcher engages directly in generating the data, or secondary, when the researcher is not involved in the generation of the original data. OSGs posts are already available and the research is not involved in the generation of the data. Therefore, it was seen as a secondary research method.

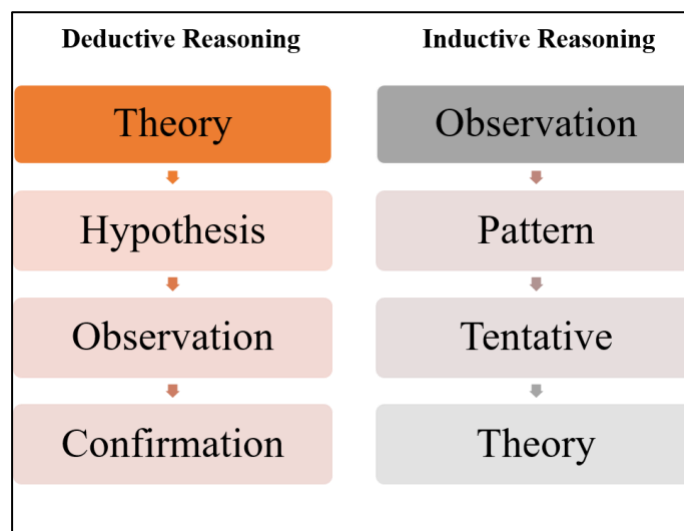
Second, the researcher conducted semi-structured, in-depth interviews with current or former OSG users to get detailed information on how the use of OSGs affects the management of their illness, either positively or negatively. Interviews were chosen as a research method because they enable interviewees to share their experiences. People were seen (by the researcher) as experts and knowledgeable about the topic under investigation, therefore, they were regarded as a valuable source of information (Bhattacharjee, 2012). Semi-structured interviews allowed researchers and interviewees to exchange dialogues informally while keeping the focus of the conversation on the topic under investigation (Mason, 2002). Additionally, they allowed researchers to design an open and flexible interview schedule so each participant's story is fully uncovered (Knox & Burkard, 2009). The flexibility provided by the interviews allowed researchers to explore expected themes as well as unexpected ones (Mason, 2002). However, it is noted that participants' characteristics, backgrounds or their desire to present the OSG in a positive way might influence the interviews (Knox & Burkard, 2009; Lewis, 2014). Therefore, the combination between the two proposed methods was expected to overcome each method's limitations.

Thematic analysis was used to analyse data collected using both methods, which allowed the research to identify themes in the data (Braun & Clarke, 2006). Thematic analysis is data driven, therefore, themes about communications in T2D OSGs can be formed directly from the data. This approach was chosen because it allows a flexible, detailed and rich description of the data and was considered appropriate with the philosophical position adopted for this study (Braun & Clarke, 2006). Previous studies that investigated OSGs have used this analysis approach to answer different questions (Attard & Coulson, 2012; Sullivan, 2003; Van Berkel et al., 2015; Van Uden-Kraan et al., 2008; Mo & Coulson, 2014). As Van Berkel

et al. (2015) described it, “this type of analysis is useful in research aimed at answering a specific research question, for the purpose of identifying, analysing and reporting themes within data” (p. 3), which was the case with the study reported in this thesis.

### 3.5 Research Approach

According to Patton (1990), there are two reasoning approaches that researchers can adopt: inductive and deductive. Inductive reasoning is typically used with qualitative research, while deductive is used with quantitative research (Creswell, 2009). In inductive reasoning, researchers produce and examine theory from the analysis of the data, whereas in deductive reasoning researchers, use the data to test a pre-existing theory (Mason, 2002) (as shown in Figure 3.2).

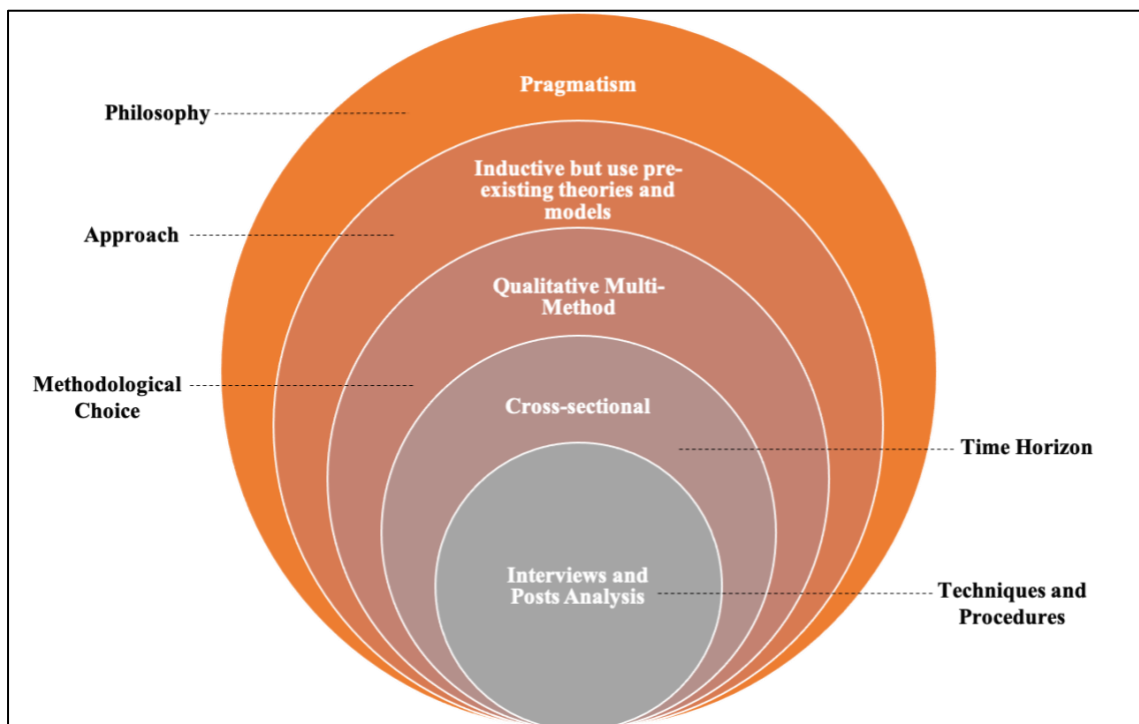


**Figure 3.2 Inductive and deductive Reasoning. Data Source: Adapted from Trochim et al. (2015)**

Since the present study was exploratory in nature, and aimed to explore and understand the implications of using OSGs on people with T2D, it naturally followed inductive reasoning. However, some of the research questions were formed based on pre-existing models (i.e. the HCE model) and the data and findings were interpreted using pre-existing theories and

models. Gray (2013) and Matthews and Ross (2010) explained that most social science studies do not follow a single reasoning approach but are developed both inductively and deductively. In this mixed reasoning approach, established theories and models could be used to make sense of the findings (Saunders et al., 2008). This is mainly because social science research is often influenced by pre-existing literature when developing research questions and interpreting findings. It can additionally develop a theory in its conclusion.

In conclusion, the present was an exploratory study that views the world from a pragmatic point of view and follows a hybrid reasoning approach that is mainly inductive in nature but used pre-existing theories and models to generate an understanding to the phenomena under investigation by undertaking a qualitative, cross-sectional multi-method. Figure 3.3 summaries the research philosophy adopted in the current study as explained in Saunders' et al. (2009) Research Onion diagram.



**Figure 3.3 The research philosophy of the current study. The diagram is adapted from Saunders et al. (2009)**

### 3.6 OSGs Recruitment and Collection of Posts

In this section, the recruitment criteria for OSGs as well as how the posts were downloaded, analysed and anonymised will be discussed.

The researcher approached several OSGs that met the following criteria to download posts from and recruit participants for the interviews:

- Written in English;
- Publicly available to read, in accordance with the The University of Sheffield's (n.d.) *Ethics policy governing research involving human participants, personal data and human tissue*. Researchers need to identify whether online posts are considered public or private to decide if informed consent is needed from users or not. According to the British Psychological Society (2013), a post is perceived as being public or private based on how the social media user who posted it perceives it. For example, when a user posts in a private group on Facebook, the post is perceived as private. More details about research ethics will be discussed in Section 3.10;
- Have an online discussion forum about diabetes;
- Have an active group (e.g. 45 or more posts in the last three months);
- Focus on the UK. Although it is not possible to limit an online space to a specific geographical location, the researcher ensured that the support groups were directed towards UK participants. There were many indications that helped him to ensure this, such as: the domain name (.uk), the terms and conditions of the website (follow the English law), the “about” section might indicate the geographical focus of the group or the majority indicated location of the participants.

People usually tend to use general-purpose search engines (e.g. Google, Yahoo, Bing) to find health information on the Internet (De Choudhury et al., 2014). Therefore, the researcher used the most commonly used search engines in the UK to identify OSGs that followed the above inclusion criteria. As of September 2017, Google, Yahoo and Bing were the most used search engines in the UK (Stat Counter, 2017; Statista, 2017). Therefore, they were used to identify OSGs for the study.

The results of the search identified three main OSGs that meet the criteria: Diabetes.co.uk (DCU), Diabetes UK (DUK) and Diabetes Support Forum UK (DSOU). The first one is the largest in size with more than 329,180 registered members. The number of registered members for the Diabetes UK (DUK) and Diabetes Support Forum UK (DSOU) OSGs was nearly 23,536 and 1,860 members respectively (see Section 3.7 for further details).

After identifying the OSGs, the researcher contacted the moderators/administrators of the groups to invite their OSG to participate in the research. All moderators initially agreed to participate in the research. After obtaining the ethics approval for the first study (see Sections 3.10 and 4.2.4), the researcher contacted them again to provide further details about the research and obtained their official consent to participate in the research and allow the researcher to collect and analyse posts from their groups. All the moderators informed the researcher with their agreement to allow the researcher to undertake the first study on their OSGs. The researcher contacted the moderators again before undertaking the interview study to obtain their official consent to recruit people for interviews. The researcher provided information sheet about the study and interviews and the ethics approval obtained for the second study (see Sections 3.10 and 5.2.6). The moderators of the three OSGs agreed to take part in the second study.

Each OSG has its own structure which differed from other groups. For instance, there were usually different forums (sections) within each OSG, such as sections for newcomers, devices for diabetes, general discussions and pregnancy. Sections that served the research aims were purposively selected and sampled. The researcher set a two-month sampling time period to limit the number of threads to a manageable amount. Within the selected sections, all data from the threads that served the objective of the study and were active during the sampling period were collected. If the volume of threads was overwhelming, the researcher might have needed to select the first 40 to 50 threads from each OSG that appear relevant. Within each thread, the researcher analysed all posts, unless the thread had hundreds of them. It is important to outline that the maximum number of threads and posts were set to guide the researcher and to avoid him to be overwhelmed with a massive amount of data with flexibility to go over them if the time allowed for that. Since the first OSG was the largest of the three communities above, in terms of number of members and posts, it was expected that the data from that OSG might have been larger than the samples from the other two groups. More details about how the first study was undertaken is explained in Section 4.2.1 and 4.2.2. The next section explains the characteristics of the identified OSGs and Section 3.8 outlines the interviewee recruitment criteria.

### **3.7 Online Support Groups Description**

As mentioned in Section 3.6, this research studied three OSGs: Diabetes.co.uk (DCU), Diabetes.org.uk (DUK) and Diabetes-support.org.uk (DSOU). Understanding the history, structure and features of an OSG may help in understanding the communication between its members. This section, therefore, will explore the history and features of each group.

### **3.7.1 Diabetes.co.uk**

Diabetes.co.uk is part of a private organisation, Diabetes Digital Media. The organisation follows a “community-profit” culture, which means it reinvests its income into creating programmes, applications, content and tools for people with diabetes (*About Diabetes.co.uk*, n.d.). The website was launched in 2003 to improve health education for people with diabetes through creating online educational programmes and interacting with other members in the forum (*Diabetes.co.uk*, n.d.). In the website’s mission, it sees people with diabetes as experts in their own condition and seeks to give them back the power through online educational programmes and forum (*Our Mission*, n.d.). This highlights the position of the website creators and moderators, which emphasises the role and uniqueness of each individual when caring for diabetes. The website offers personalised educational programmes and recipes and, in the forum; it emphasises how every individuals are responsible for caring about their diabetes. The website has the largest number of users and visitors among the three OSGs with an average of 2.70 million visitors each month (average from April to September 2018). Besides the forum, the website offers three other main services for its visitors: information content about diabetes, educational programmes and applications and marketplace. The website offers a large number of information content, created by the website editors, about different aspects of diabetes (e.g., diabetes types, symptoms, tests, medications, equipment, diet). The information is presented in the form of text, pictures, infographics and videos. The educational programmes and applications offer personalised coach to their users to help them to manage different aspects of the condition (e.g. Hypo Awareness Program, Low Carb Program, Recipe App and DiabetesPA). While some programmes are free, others are not. For example, the marketplace offers a range of products from diabetes books to equipment to monitor the condition (e.g. test strips, blood glucose meters, insulin pens). It also offers



insurance services for people with diabetes (through a partnership with other insurance parties).

The forum was launched in 2007 to connect people with diabetes together (*Our Mission*, n.d.). With more than 329,180 members (as of December 2020), the forum was considered to be the largest diabetes community in Europe (*Diabetes.co.uk*, n.d.). The forum offers 44 sections (boards) for members that range from general ones (e.g. Type 1, Type 2) to more specific ones (e.g. Newly Diagnosed, Low Calorie Diets, Emotional and Mental Health, Driving and DVLA). With web and phone-application versions, the forum has more than 8,000 monthly new members, 15,000 daily visitors and 4,000 daily posts (A. Panesar, personal communication, October 25, 2017).

### ***3.7.2 Diabetes.org.uk***

The charity started as The Diabetic Association in 1934, changing into the British Diabetic Association in 1954, before becoming known as Diabetes UK in 2000. Its main vision was to ensure that people in the UK could have the needed knowledge and treatment about diabetes regardless of their financial status (*Our History*, n.d.). DUK believes that everyone has the right to access health services and it was one of the organisations that campaigned for the establishment of the NHS (*Our History*, n.d.). Additionally, the organisation believes that people with diabetes should be active in managing their illness and has established a wide network of volunteers across the country that organises events and support sessions for people with diabetes to provide information and emotional support.

Unlike DCU, DUK started a long time before the era of the Internet as a charity that aims to support people with diabetes and ensure they get equal access to health care services. The charity became the voice for people with diabetes in the UK and has campaigned for their

health rights such as: getting test strip prescriptions, receiving the education needed to manage the condition, knowing the nutrition content of food and drinks in restaurants and supermarkets (*Campaigning*, n.d.). Moreover, DUK funds research that aims to prevent and cure diabetes. With more than 130 projects that cost approximately 25 million pounds, the organisation is considered one of the main funders of diabetes studies in the UK (*Our Research*, n.d.). The organisation has formed a large community of volunteers across the UK that organises face-to-face support groups and other events such as fundraising and raising awareness events (*Volunteering*, n.d.). The organisation focuses on including minorities in DUK's community to ensure they are receiving the support they need. Additionally, DUK offers a helpline that provides information, emotional, legal and psychological support for people with diabetes and their family and friends (*Diabetes UK Helpline*, n.d.).

The charity also has a website that contains information about diabetes, its prevention and management. The website has a marketplace where diabetes-related and not diabetes-related items are sold. It also accepts donations from visitors to fund the charity. The website contains a forum that allows people with diabetes to exchange experiences and information. The forum has 18 sections (boards) and, unlike DCU, it does not offer separate sections (boards) for each type of diabetes but only a general one. The forum has 23,356 members (as of December 2020).

### ***3.7.3 Diabetes-support.org.uk***

DSOU was started in 2007 as an online peer support group by two people with diabetes. The purpose of starting the forum was to provide a friendly and supportive online space connecting people with diabetes in the UK and allowing them to exchange experiences and information (Diabetes Support Forum UK, n.d.). The website creators intentionally decided

not to join or collaborate with any organisation to avoid adopting or promoting their philosophy/agenda. They also decided not to accept advertisements and sponsorships for the same reason. The website now contains an information section, which came after the creation of the forum. The information section was created to meet forum users' needs. Some information and links to external sites were referred to more often in the forum, so the website now includes an information section with this content. The forum has a total of 1,860 members (as of December 2020). The forum contains 23 sections (boards) that range from general topics (e.g. General discussion) to more specific ones (e.g. Breakfasts, Desserts, Snacks).

#### ***3.7.4 Conclusion***

In conclusion, DCU is the largest OSG in size compared to DUK and DSOU. While DUK is a charity established many years ago to enable people with diabetes, DCU and DSOU started as online platforms for people with diabetes. On the one hand, DCU is a private organisation with a business model that aims to generate revenue from some of the services on the website. On the other hand, DSOU is a very small, independent website without links or collaborations with other parties and without a marketing agenda.

### **3.8 Interviewee Recruitment**

After the first study was undertaken, the researcher contacted the moderators of the three OSGs again to obtain their consent to participate in the interview study. The invitation contained an information sheet about the study and the ethics approval obtained for the interview study (see Sections 3.10 and 5.2.6). After receiving the permission from OSG moderators to recruit participants from the groups, an invitation to participate in the interviews was posted in the groups. The inclusion criteria were as follows:

A participant had to:

- Have been diagnosed with T2D.
- Have been a current or former OSGs users (not friends or family members of a user). They must have used the OSG for at least two months, so the OSG can have effect on them.
- Have been a poster or lurker. Previous studies have shown that OSGs can affect both posters (those who post on OSGs) and lurkers (those who do not post) (Petrovčič & Petrič, 2014; Preece et al., 2004), therefore, a participant could be either a poster or a lurker.
- Speak English.
- Have been 18 years or older.
- Have lived in the UK for at least the past six months.

Participants were recruited based on a first come first served basis. The variety of representations of the participants was reviewed and to try and ensure that they were not homogenous. If the participants were homogenous in any way, the researcher would have used the same recruitment method, but targeting a group of people that had not been covered in the previous sample.

In terms of the sample size for the interviews, the researcher continued conducting interviews until data saturation was achieved. When no new relevant findings/data seemed to be emerging from the interviews, the themes were well developed and the relationship among the themes were well established and validated, the researcher took a few more interviews to assure the data saturation was reached and then stopped conducting interviews. Strauss and Corbin (1998) explained that “saturation is central to qualitative sampling” (p. 5). Guest,

Bunce and Johnson (2006) added that “saturation has become the gold standard by which purposive sample sizes are determined in health science research” (p. 60). The researcher needed to combine sampling, data collection and data analysis to identify when the saturation point was achieved (Bryman, 2003). However, the researcher estimated that the data saturation to occur after undertaking 15 to 25 interviews, as suggested by Baker and Edwards, (2012).

The researcher collected information about interviewees' demographic details and their social, economic and educational status, as well as length and nature of time they had been using the OSG, to be taken into account during the analysis process. This information about the interviewee's background might provide insights into how they experienced and viewed empowerment. Further details about the data collection for the Interview Study are discussed in Section 5.2.4.

### ***3.8.1 Interviews piloting***

Before conducting the interviews, the researcher tested (piloted) the interview questions on supervisors and colleagues to test the clarity of the questions and amend them if necessary. It is a highly advised step to reduce any ambiguity in the question and address any technical issues as well as to allow “some assessment of the questions' validity and the reliability of the data that will be collected” (Saunders et al., 2008, p. 597). This resulted in rephrasing some questions to make the questions clearer for the interviewees. More details about interview piloting are explained in Section 5.2.3.

### 3.9 Data Analysis

Data analysis in qualitative studies aims to make sense of the data (Merriam & Tisdell, 2009) and generate knowledge about the studied phenomena (Thorne, 2000). The researcher, therefore, has to make a number of decisions about how to interpret the data, develop meaningful themes and present them (Patton, 2002). Thematic analysis was used in analysing posts and interview transcripts, and is considered as a primary technique for qualitative studies (Braun & Clarke, 2006). Thematic analysis is a process for encoding qualitative information (Boyatzis, 1998). It provides a “flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data” (Braun & Clarke, 2006, p. 78). A theme that is discovered through thematic analysis is defined as “a pattern in the information that at minimum describes and organises the possible observations and at maximum interprets aspects of the phenomenon” (Boyatzis, 1998, p. 4). Themes can be identified inductively, without fitting the data to pre-existing themes, or deductively, by fitting the data into a pre-existing *codebook* (Boyatzis, 1998; Braun & Clarke, 2006).

Thematic analysis is not related to a particular philosophy and epistemology and can be used in multi-epistemological and -theoretical approaches (Braun & Clarke, 2006). For the present research, thematic analysis was seen appropriate because: (1) it fits the adopted research philosophy, (2) can provide a rich and detailed information about the research questions and (3) can be used either inductively or deductively to connect the current research with previous studies. Thematic analysis has been widely used in analysing posts and interview transcripts regarding OSGs (Gooden & Winefield, 2007; Greene, Choudhry, Kilabuk, & Shrank, 2011; Lovatt, Bath, & Ellis, 2017; Mo & Coulson, 2014; Peel, Parry, Douglas, & Lawton, 2004; Rupert et al., 2014; Sullivan, 2003; Van Berkel et al., 2015; Van Uden-Kraan et al., 2008). Van Berkel et al. (2015) explained that “this type of analysis is useful in

research aimed at answering a specific research question, for the purpose of identifying, analysing and reporting themes or patterns within data” (p. 3).

The analysis of data for the current study followed Braun and Clarke's (2006) six steps for conducting thematic analysis which can be summarised as follows:

1. Exploring and knowing the data: this step aims to immerse the researcher with the collected data. This can be achieved through transcribing (if necessary), reading and re-reading the data with writing down initial ideas. This step suggests that the researcher immerse him-/herself in the data to become “familiar with the depth breadth of the content” (Braun & Clarke, 2006, p. 87).
2. Producing the first version of codes: this step starts when a familiarisation with the data was reached and a list of what the data contained was noted (Braun & Clarke, 2006). Interesting features across the whole data set are captured in codes in this step. This systematic approach aims to capture all possible patterns in the data set. The coding process aimed to identify features of interest that could be assessed in a meaningful way and organised into meaningful categories (Braun & Clarke, 2006). In this stage, Braun and Clarke (2006) recommended coding all potential patterns with keeping a little of the related surrounding data to save the context of the data.
3. Looking for themes: codes from the previous step are collated in this step into potential themes. This step involves looking at the data at a broader level to sort the identified codes into potential themes. In this phase, “how different codes may combine to form an overarching theme” are examined (Braun & Clarke, 2006, p. 89). This includes looking at the data at a broader level, “sorting the different codes into potential themes, and collating all the relevant coded data extracts within the identified themes” (Braun & Clarke, 2006, p. 89).

4. Examining and evaluating the themes: this step aims to review and then refine the themes at the level of the coded data extracts and then at the level of the whole data set. This step involved “checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic ‘map’ of the analysis” (Braun & Clarke, 2006, p. 87). Generally, this step includes performing two main tasks: first to review and then refine the themes at two levels (at the level of the coded data extracts and then at the level of the entire data set). The thematic map is then produced.
5. Identifying and labelling the themes: the essence of each theme is identified in this step. This includes defining what each theme includes and naming the themes to make them representative of their content.
6. Writing the report: This step involves the write-up and presentation of the themes. This process should provide a “concise, coherent, logical, non-repetitive and interesting account of the story the data tell within and across themes” (Braun & Clarke, 2006, p. 93). This includes the selection of vivid and compelling examples from the data and relating the analysis to the research questions and literature. The presentation of the themes in this study can be found in Section 4.3.2 and Section 5.3.2.

Further details about how these steps were carried out in this thesis are explained in Section 4.2.2 and Section 5.2.5.

It is expected that some of the themes found from analysing posts also appear when analysing interview transcripts. Data units might have been assigned to multiple codes if they seem to



belong to different ones. This helped the researcher to understand patterns more clearly (Gooden & Winefield, 2007).

### **3.10 Ethical Issues**

Hesse-Biber and Leavy (2010) explained that researchers must anticipate all ethical issues that might arise during their research. They must address these issues as well as perform all required steps to protect their participants (Creswell, 2009). This section will outline all anticipated ethical issues and illustrate how the researcher addressed them.

The OSG posts study involved collecting and analysing online posts. This entailed considering several issues. First, although the majority of OSGs are public, the groups' administrators/moderators were contacted to request a permission to analyse the posts (as explained in Section 3.6). Second, it is critical to note that the researcher considered the norms of the OSG and the likelihood of being observed as intrusive, as illustrated in The University of Sheffield's (2016) Ethics Policy. Third, members of the groups were anonymised and could not be identified in the research (as Section 4.2.4 outlines).

Additionally, any quotes from the posts used in the research were paraphrased to ensure that members of OSGs could not be traced via search engines. All of the ethical issues that might arise in conducting this stage of the research have been discussed in greater detail in the ethics application that was submitted to the University of Sheffield's Ethics Committee (Appendix 1). Ethical approval for conducting and analysing online posts from diabetes OSGs was successfully obtained following the first application in 17/11/2017 (Appendix 2). After obtaining the approval, moderators were contacted to obtain their consent to allow the researcher to collect and analyse posts from their OSGs. They were provided with an

information sheet (Appendix 3) that explained what and how the study was planned to be carried out. The moderators from the three OSGs agreed to take part in the first study.

In terms of conducting the interview study, the participants had the right to choose whether to take part in the study or not (The University of Sheffield, 2016a). As illustrated in the policy, “consent must be given freely and voluntarily and under no circumstances must direct coercion or indirect pressure be used to obtain a person’s consent to participate in research” (p. 25). Therefore, the researcher obtained a consent form from the participants which explained the rights of participants. The security, confidentiality and anonymity of the data was ensured when collecting, analysing, reporting and storing the data.

The researcher ensured that the participants, as well as himself, were not exposed to any risk or harm when conducting the study. There is always a risk with conducting face-to-face interviews with strangers. Thus, it was important to meet participants in a public space, such as the University or a coffee shop. The preferred option was to meet them in any available meeting room in the Information School. If the interviewee preferred not to come to the University, the researcher had planned to contact a public library near to the interviewee to reserve a meeting room with adequate privacy, or a similar suitable location. It was important to ensure that the building was friendly and well equipped for people with disability. Participants were given the option to be interviewed either face-to-face, by phone/Skype or email. Sections 5.2.2 and 5.2.4 explain how the interviews were undertaken. Further details about all ethical issues that might have arisen from the Interview Study is explained in the ethics application that was submitted to University of Sheffield’s Ethics Committee (Appendix 4). Ethical approval for undertaking the interview study was successfully obtained following the first application in 29/08/2018 (Appendix 5). The moderators were then

contacted with a copy of the ethics approval and information sheet (Appendix 6) to obtain their approval to allow the researcher to recruit participants for the second study. The moderators of the three groups agreed to take part in the interview study.

Further details about how ethical issues were considered are explained in Section 4.2.4 and 5.2.6.

### **3.11 Research Quality**

Trustworthiness is essential to ensure that the research questions are accurately answered and the quality of the research, in general, is appraised (Saunders et al., 2008). In qualitative studies, trustworthiness is often used to refer to the validity, reliability, credibility, dependability and transferability of the study (Lincoln & Guba, 1985; Polit & Beck, 2008; Seale, 1999). These criteria will be discussed in this section.

First, validity is the main criterion for evaluating the quality of a study (Bryman et al., 2007). It is defined as “how accurately the account represents participants’ realities of the social phenomena and is credible to them” (Creswell & Miller, 2000, p. 124). It enables the researcher to check for the accuracy of the findings by employing specific procedures (Creswell, 2009). Reliability, on the other hand, ensures that the research process is consistent across other researchers (Gibbs, 2007). A qualitative study is considered reliable if the same results can be achieved by other researchers (Lewis, 2009). Researchers thus are advised to document with precision their field notes and decision points to allow future researchers to replicate the research (Lewis, 2009; Schwandt, 2007). Third, credibility refers to the “confidence in the truth of the data and interpretations of them” (Polit & Beck, 2008, p. 539). Guba and Lincoln (1994) explained that credibility in qualitative studies includes the

following two parts: (1) the research should be undertaken in a way that improves the believability of the results; and (2) researchers should provide a demonstration to readers of the steps that they took to ensure credibility. Fourth, dependability aims to evaluate whether the research findings can be repeated if the same (or similar) procedure (e.g. participants, context) is followed. To reach that, Lincoln and Guba (1986) recommended researchers to record a step-by-step document of the research process and its decisions. This, therefore, will serve as an auditor to the study and enhance its dependability. Lastly, transferability seeks to evaluate the generalisability of the findings. In particular, it refers to the extent to which the findings of the study can be transferred elsewhere to other similar contexts or groups (Polit & Beck, 2008). Tracy (2010) explained that researches can achieve transferability through providing a rich description of the research assumptions, context and processes.

To ensure the trustworthiness and quality of this study, a number of steps were undertaken. First, regular documented meetings with the research team (i.e., the supervisors) were maintained to ensure that the data were collected, analysed and interpreted accurately (Lincoln & Guba, 1986). This enhanced the credibility and validity of the study. Second, before starting this study, the researcher was not familiar with the context of the study (i.e., he did not live in the UK, nor have T2D and was not familiar with the selected OSGs). Bolak (1996) suggested that native researchers need to distance themselves from a familiar environment to ensure their objectivity. For this study, the researcher was not familiar with the environment of the study which, therefore, ensured the objectivity and credibility of the study. Third, the researcher triangulated different data sources (posts and interviews) to build a coherent justification for the findings of the study. Eisner (2017) explained that data triangulation provides “a confluence of evidence that breeds credibility” (p.110). Fourth, the researcher provided a rich and detailed description to convey the findings. This included

details about the design of the study (e.g. characteristics of the participants), context, settings and study processes. This ensured that others can judge the transferability of the study. Fifth, the researcher kept a full record of the documents and evidence of the research process such as ethical approvals and applications and participant information sheet and consent. This also included the raw data from both studies (i.e. OSG posts and interviews recordings and transcriptions). This guaranteed the dependability of the study and that the findings could be repeated if the same procedures were followed. Sixth, inter-coding reliability was undertaken for the OSG posts study (see Section 4.2.3). It refers to “the extent to which independent coders evaluate a characteristic of a message or artefact and reach the same conclusion” (Lombard et al., 2010, p. 589). Inter-coding reliability is widely used in various disciplines to validate subjectively-coded data (Freelon, 2010). Lombard et al. (2002) recommended that at least 50 units or 10% of the data should be checked by coders and Miles and Huberman (1994) suggested that coders should be at least 80% consistent. Seventh, to enhance the validity, credibility and transferability of the interview study, member checking was applied. Member checking, also known as participant validation, can be used to evaluate and verify the trustworthiness of qualitative studies (Doyle, 2007). It involves sharing the main findings of the qualitative study with the participants and let them determine if the findings are accurate and represent their voice or not (Creswell, 2009). However, the participants may “cling to their own perspectives and disagree with your conclusions and interpretation, but these readers should have the opportunity to challenge a study’s key findings” (Yin, 2003, p. 199). In case of disagreement, Yin suggested that the researcher may seek further evidence to settle the disagreement. In this study, the researcher shared a summary of the main findings with the participants of the interview study (see Section 5.2.7) to gain their feedback on the findings.

### **3.12 Conclusion**

This chapter outlined how the research questions were going to be answered by outlining the research paradigm (Section 3.2), methodology (Section 3.3), method (Sections 3.4) approach (3.5), recruitment criteria (Sections 3.6 and 3.8), data analysis procedure (Section 3.9), ethical issues (Section 3.10) and research quality (Section 3.11). The next chapter will present the first study of the thesis.

## **CHAPTER 4 : HEALTH ONLINE SUPPORT GROUPS POSTS STUDY**

### **4.1 Introduction**

The previous chapter explained the methodological approaches of the study. This chapter presents the findings of the first stage, the thematic analyses of the OSG threads and posts. This chapter first explains the methods used to collect, analyse and anonymise the data from the three OSGs as well as the ethical considerations (Section 4.2). It then presents the findings of the thematic analysis (Section 4.3). Lastly, the chapter presents a discussion of the findings in relation to the literature and theoretical framework (Section 4.4).

### **4.2 Methods**

#### ***4.2.1 Data Collection***

As Sections 3.10 and 4.2.4 explain, informed consents were obtained from the moderators/owners of the three OSGs before the data collection. Threads and posts that were posted during the sampling period, which was from the beginning of June to the end of July 2017, were purposively collected. This time frame was intentionally set to be in the past (i.e. a year prior data collection) to minimise potential harm to members (see Section 4.2.4) and to include a typical sample (e.g. not a public holiday season). Each OSG has a different structure (e.g. different boards and sections). For example, one of them had separate sections for newly diagnosed people, diet, food and nutrition and legal rights. However, all of them had a general discussion section/board where members can discuss all topics. The general sections tend to be the most used ones. The focus was on the threads and posts in the general sections of the OSGs to allow the researcher to investigate broadly how the OSGs were being used with considering all possible topics. Only threads and posts created by members who have T2D were included and others people's posts (e.g. family members and carers) were excluded from the sampling. This information about how members were associated with

diabetes was shown in their profiles. As explained in the previous chapter (Section 3.6), the sample collected from the three OSGs was purposively selected. This was due to the overwhelming volume of threads in the sampling period. The data collection focused on threads that clearly showed how the use of the OSGs helped people with T2D to manage their illness and overcome social, environmental and intrapersonal barriers. The collected threads and posts also showed the main concerns and challenges that people with T2D face on a day-to-day basis when managing diabetes. The purposive collection of the data helped the researcher to obtain a deeper understanding on how OSGs can influence members' empowerment.

The data were downloaded from the three OSGs websites as portable document format (PDF) documents. Threads that included several pages were downloaded as multi-PDF files then merged into a single file. For anonymisation purposes, members' names were replaced with numbers (see Section 4.2.4) and gender information was recorded.

## ***4.2.2 Data Analysis***

As described in Section 3.9, his study followed Braun and Clarke's (2006) six-step approach towards thematic analysis. The researcher had to take several decisions when analysing the data as explained below.

### ***4.2.2.1 Familiarisation with the data***

Prior to starting the data collection, familiarisation with the literature in the area of study was carried out (King et al., 2018; Zarotti et al., 2019). The literature led to understanding the context of the study and provided some understanding on the type of the data that would be expected to emerge from the data collection. The researcher then spent enough time to



familiarise himself with the content of the data before, during and after collecting them. This included reading and re-reading the data, searching for similar concepts and taking notes about coding ideas. The notes became useful during the analysis phase as they provided the researcher with detailed descriptions and ideas that ensured richer data.

#### 4.2.2.2 *Generating initial codes*

The data were imported to the qualitative data analysis software NVivo 11 to help the researcher manage the data and generate initial codes (Bryman, 2012). The process of coding started with an inductive open coding to allow the data to speak for itself (Bryman, 2012). However, the HCE model (Johnson, 2011) provided some insights and ideas that were used in generating initial codes. Depending on the context, a given data extract was either left uncoded, coded once or coded multiple times (Braun & Clarke, 2006) as shown in the example in Table 4.1 below.

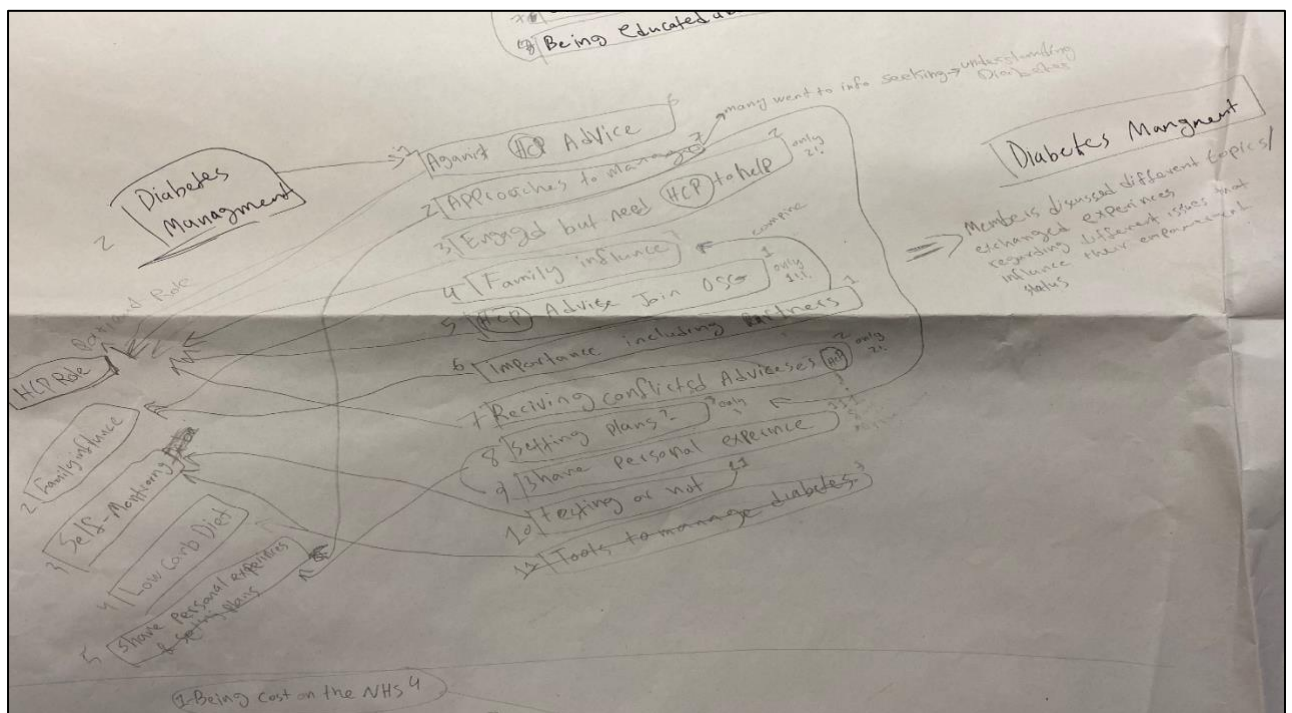
**Table 4.1 Example of data coding**

<b>Data extract</b>	<b>Coded for</b>	<b>Rationale</b>
<i>“Yes this is me in the avatar picture, I used to have another picture but I changed it”</i>	Uncoded	Not directly related to T2D
<i>“I remember when I was young when there were very few things to watch on TV”</i>		
<i>“I feel that there are many factors a patient can control in T2D such as diet and exercise to minimise the risk of complications”</i>	Patients’ role	User indicating extent to which they might control the condition
<i>“TBH, I don’t believe the medical advice about Diet. When I eat potatoes, they raise dramatically my blood sugar”</i>	Low-carb diet (knowledge debate)	Mention of blood sugar
	Sharing experiences	Relating own experiences

The initial coding resulted in 63 codes that captured all prospective themes. These codes uncovered several initial patterns and were labelled to create categories. The list of codes was reviewed and revised to identify and eliminate repetition and overlapping. This systematic process was continuous and iterative and involved note taking to ensure that potential themes were produced meaningfully. The developed codes were checked with another coder to ensure the consistency of the coding process as Section 4.2.3 outlines.

#### 4.2.2.3 Searching for themes

In this step, the codes were collated and arranged to form potential themes. Mind-maps were used to help the researcher to sort the different codes into themes (Figure 4.1). Ideas and notes taken in the previous stages were used at this stage to identify potential themes.



**Figure 4.1 Initial thematic map organised using mind-maps to understand relationships between the codes.**

This technique is widely used in qualitative studies because it helps the researcher identify “interlinked, interrelated, interdependent and even tangled” concepts as well as the

relationship between them (Cassell & Symon, 2004, p. 79). At this stage, whilst some codes might form main themes, others might form sub-themes or be discarded. Other codes, however, might not belong to any of the previously identified themes. Therefore, it was advised to create a theme called “others/ miscellaneous” to hold them temporarily (Braun & Clarke, 2006).

As a result of this stage, nine main initial themes emerged from the data:

1. *Benefits of Using OSGs.*
2. *Disadvantages of Using OSGs.*
3. *Diabetes Management.*
4. *Emotional Support.*
5. *Seeking Advice.*
6. *Providing Advice.*
7. *Knowledge Debate.*
8. *Sharing News.*
9. *Sharing Thoughts, news, updates and Emotions.*
10. *Others*

#### **4.2.2.4 Reviewing themes**

The researcher firstly read the collated extracts for the initial themes and checked whether they formed a coherent pattern (i.e. if there were enough data to support them or if they were related to other themes). The review also investigated whether the content of the themes was different or not and whether it was required to break them down into different themes. This included checking that the data within themes “cohere together meaningfully” and a clear distinction between themes was identified (Braun & Clarke, 2006, p. 91). As a result, a number of decisions were made. For example, if two themes fitted with each other, they were merged to form one theme. New themes might be created in this stage to host those data extracts that did not fit with the already-existing themes. Other data extracts might be deleted from the analysis. After that, a candidate thematic map was developed to capture all themes. The validity of each theme was then checked in relation to the entire data set. The thematic

map was also checked to determine whether it “accurately reflects the meanings evident in the data set as a whole” (Braun & Clarke, 2006, p. 91).

The two initial themes *Seeking Advice* and *Providing Advice* were merged to form the theme *OSGs as a Source of Information*. Two other themes were emerged to form one theme *Sharing Emotions and Experiences*. However, another theme, *Disadvantages of Using OSGs* was discarded because the data were too diverse and not enough. The outcome of this step was the following final themes:

1. *Benefits of Using OSGs.*
2. *Diabetes Management-Related Issues.*
3. *Knowledge Debate.*
4. *OSGs as a Source of Information.*
5. *Sharing Emotions and Experiences.*

#### ***4.2.2.5 Defining and naming themes***

In this step, themes were defined to determine the content of each them and then they were named to represent their content. Table 4.2 presents the Final themes and their descriptions.

**Table 4.2 Main themes that emerged from the thematic analysis**

<b>Theme</b>	<b>Description</b>
<i>1. Benefits of Using OSGs</i>	Threads and posts that clearly state how the informational and emotional support received in the OSGs impacted positively in the management of the illness for members.
<i>2. Personal Management of Diabetes-Related Issues</i>	Threads and posts that show issues that influence the person's own management of different aspects of diabetes and members' empowerment.
<i>3. Knowledge Debate</i>	Threads and posts that contain arguments about how knowledge about certain topics that influence diabetes were perceived from members and HCPs.
<i>4. OSGs as a Source of Information</i>	Threads and posts that contain questions and answers relating to information they needed from members to others.
<i>5. Sharing Emotions and Experiences</i>	Threads and posts that contain members' expressions on how they think and feel about having diabetes, updates on their diabetes status, emotional support and their plans to manage diabetes.

#### **4.2.2.6 Producing the report**

Section 4.3 presents the overall findings and discussion of the analysis of this study.

#### **4.2.3 Inter-coder reliability**

As Section 3.11 outlined, inter-coder reliability was applied in this study to ensure coding consistency. A second coder (a colleague in the Information School at the University of Sheffield studying for a Ph.D. in information science) was trained to examine the anonymised data and help ensure the reliability of coding and achieving an accurate analysis. The inter-coding process was undertaken in two stages. As explained in Section 3.11, and recommended by Lombard et al. (2002), a 10% sample of the data was examined by the second independent coder in each stage. The sample was randomly selected at each stage. Inter-coding was measured by two measurements: (1) the agreement percentage between the two coders; and (2) the Cohen's kappa coefficient that calculates the inter-rater reliability for

qualitative items (Lavrakas, 2008; LeBreton & Senter, 2008). In order to calculate these measurements, a web service called ReCal (Freelon, 2010) was used. Lavrakas (2008) and Allen (2017) explained that acceptable levels of agreement between the two coders may range from between 70% to 90% or greater depending on the nature of the study (i.e. 70% or greater is considered acceptable in exploratory studies, 80% or greater may be acceptable in most studies and 90% or greater is acceptable in nearly all studies). In social science research, Joyce (2013) considered an agreement of 80% between two coders as reliable. Cohen's kappa coefficient, in contrast, is considered acceptable if it is 0.70 or greater (Mayring, 2000; Syed & Nelson, 2015).

The first stage was undertaken after generating the initial codes (Section 4.2.2.2). In this stage, the agreement between the researcher and the second coder was 83.5% and Cohen's kappa coefficient was 0.831. As explained previously, this level of agreement is considered acceptable. In fact, LeBreton and Senter (2008) considered this level of agreement as strong agreement and Fleiss (1981) explained that a kappa coefficient of 0.75 and above is excellent. This stage also allowed the researcher to receive feedback and comments from the second coder regarding the coding process and, from this discussion, the second coder's experience. As a result, this helped the researcher to enhance the coding process. For example, there was a disagreement between the researcher and second coder regarding overlapping that occurred between some codes. In particular, there was confusion regarding the initial benefits of using OSGs (e.g. fulfilling information needs) and the ultimate benefit/ result of this (e.g. the successful control and management of the condition). As a result, some codes were refined and rearranged to improve the coded categories. Codes that were seen as initial and ultimate benefits were combined and grouped separately. The improvement of the coding scheme that resulted from this step was applied to all of the coded data.

The second stage of inter-coding was applied following completion of the fourth step of thematic analysis as explained in Section 4.2.2.4. The same second coder was also trained to code the data. Subsequently, they were then provided with a sample that contained 10% of the data. The second coder was then asked to code the sample independently. This resulted in an agreement of 88.2% and a Cohen's kappa coefficient of 0.872 between the researcher and the second coder. As explained earlier, this is considered as evidencing a substantial level of agreement. Similar to the first stage, disagreements between the second coder and researcher were discussed and resolved.

In conclusion, despite the controversial debate between various scholars about whether or not inter-coder, reliability should be carried out in qualitative studies (e.g. Guba & Lincoln, 1994; O'Connor & Joffe, 2020; Peterson et al., 1999), this measurement allowed the researcher to look at the data and codes from another perspective and ensure that the analysis provided a meaningful interpretation, one that is extended beyond the researcher.

#### ***4.2.4 Ethical Considerations***

As Section 3.10 explained, this stage of the study was ethically approved in accordance with the University of Sheffield research ethics policy (see Appendix 2 for the ethical approval). Although the data were publicly available, informed consent was obtained from each of the administrators of the three OSGs. They agreed to allow the researcher to collect and analyse the threads/posts. Researching live, current, online activities might have a greater harm of identifying users and altering their behaviours (The University of Sheffield, 2016b). To minimise this harm, the study was limited to activities that took place in the past, i.e., the sampling time period was set to be June to July 2017 and the data collection was undertaken

a year later. Since the data were publicly accessible, the risk of identifying members was considered. Therefore, quotes reported in the chapter and in subsequent publications were rephrased to ensure that members could not be identified by using search engines. Additionally, members' names were replaced with numbers at the time of the data collection and a record of members' names and numbers was kept encrypted. Members were then assigned random aliases. Members' gender was considered when the aliases were assigned. When the gender was not provided, a random name was assigned. Each alias is unique within the same OSG but might be repeated across the other OSGs. Therefore, a reference system that contains the OSG number and alias was used to refer to the OSG and members in this chapter as explained in Table 4.3.

**Table 4.3 Guide of Members' Reference System**

<b>OSG</b>	<b>OSG's Number</b>	<b>Member's Alias (example)</b>	<b>The Complete Reference Code</b>
<i>DCU</i>	<i>1</i>	<i>David</i>	<i>1- David</i>
<i>DUK</i>	<i>2</i>	<i>Sarah</i>	<i>2- Sarah</i>
<i>DSOU</i>	<i>3</i>	<i>Ana</i>	<i>3- Ana</i>

The collected data were then analysed by following Braun and Clarke's (2006) six phases of thematic analysis, as explained in Section 3.8. The qualitative analysis programme NVivo 11 was used to store, manage and code the data.

## **4.3 Results**

### ***4.3.1 Description of the OSGs Sample***

A total of 76 threads and 738 posts from 250 unique members was purposively collected and analysed from all three OSGs. Due to the different sizes of the OSGs, approximately 70% of the sample came from DCU, 25% from DUK and 5% from DSOU. As explained in Section



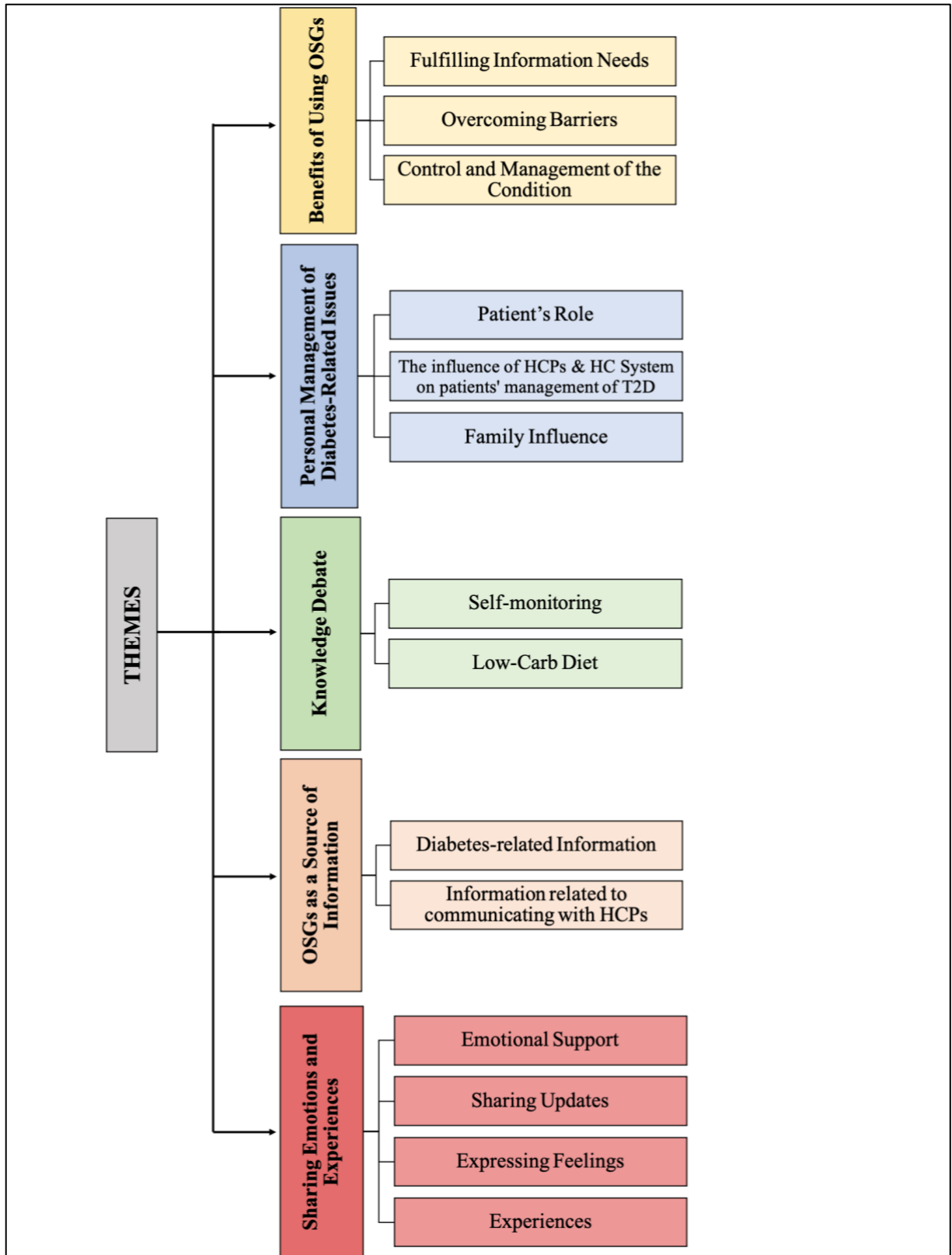
3.7, the size of DCU was much larger than DUK. DSOU, on the other hand, was a very small community compared to the other two. The majority of members who had posted in the collected sample were females (51%), 35% were males and 14% did not provide gender information (the details are summarised in Table 4.4). This was not altogether surprising since females tend to be more active than males in online health communities (Yan et al., 2014).

**Table 4.4 Summary of the collected sample from the three OSGs**

	<b>DCU</b>	<b>DUK</b>	<b>DSOU</b>
<b>Total number of threads from June to July 2017</b>	214 (Type 2 only)	445 (all types)	24 (all types)
<b>Total number of threads by members with T2D from June to July 2017</b>	214	227	5
<b>Total threads included in the sample</b>	53	19	4
<b>Inclusion rate</b>	25%	8%	80%
<b>Total posts included</b>	526	183	29
<b>Total number of members in the sample</b>	173	61	16
<b>Sample gender</b>	39% Male 49% Female 12% Not provided	28% Male 61% Female 11% Not provided	19% Male 37% Female 44% Not provided

#### ***4.3.2 Health Online Support Groups Posts Study Results***

Five main themes emerged from the thematic analysis of the OSGs data: Benefits of using OSGs, Personal Management of Diabetes-Related Issues, Knowledge Debate, OSGs as a Source of Information and Sharing Emotions and Experiences. Each theme consists of sub-themes as shown in the thematic map in Figure 4.2.

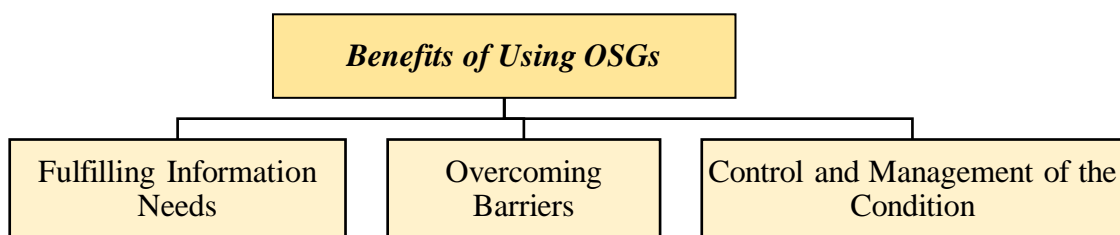


**Figure 4.2 Map of the themes and subthemes identified through thematic analysis**

This chapter presents a description of the themes, evidenced by using paraphrased parts of the threads and posts of members' thoughts, feelings and experiences shared in the forums.

#### ***4.3.2.1 Benefits of Using OSGs***

This theme includes threads and posts that show how OSG members used online forums to overcome different barriers and to understand and manage the condition. It consists of three sub-themes as illustrated in Figure 4.3.



**Figure 4.3 Subthemes of the theme: Benefits of Using OSGs**

##### ***4.3.2.1.1 Fulfilling Information Needs***

This sub-theme shows how members in the OSGs fulfilled their information needs about different aspects that influence their understanding of diabetes, which resulted in satisfying a knowledge gap about the condition. Many members, on occasion, stated that the OSG was the main information source they used to obtain information about the condition. The use of OSGs as an information source helped many users to overcome the lack of information by HCPs, to know about treatment options and techniques that were not introduced by HCPs, either because they did not agree with them or did not have the time to do so, and to find information about where to find affordable tools and equipment. For example, members stated how they discovered new information about different issues through using OSGs. They compared the knowledge they received from the OSG with other sources of information (e.g., HCPs, educational courses) and that they had before joining the online platform. Following are some examples of such views:

*“Through the past years, I have learned from this OSG way more than I learned from my HCPs, my advice is to use this OSG as your primary information source” (2- Emily)*

*“I am learning many things about my Type 2 diabetes, all from this OSG” (1- Alexis)*

*“I’m thankful for finding this OSG, before finding it, I knew very, very little, now I’m totally different and still learning every day from the OSG” (2- George)*

*“What I have learned from this OSG is far more than anywhere else” (2- Isabella)*

*“I have learned a lot from this OSG, much more than my HCPs and the useless educational course they recommended, and I attended” (1- Nora)*

The information and experiences shared in the OSGs helped some members to become aware about their unhealthy living habits, which had resulted in their diabetes being poorly managed. For example, Thomas was struggling to manage the condition after being newly diagnosed, and the OSG helped him obtain the information he needed to cope with it. This member mainly acquired information about how to maintain a healthy weight, the influence of unhealthy food and drinks on diabetes and the importance of being active:

*“Four months ago, I was diagnosed with diabetes with HbA1c of 54, I was completely inactive and unhealthy eater, I was fortunate enough to find this OSG directly after that, it helped me to learn about effective diet options which helped me, together with walking every day” (1- Thomas)*

The platforms were helpful to many members, especially for obtaining information about diet options, such as the low carbohydrate (low-carb) programmes, which they did not know about. This is mostly because there is considerable debate around such programmes and the NHS does not support this approach (NHS, 2016c). Some members, for example, reported their understanding of different low-carb programmes from other members in the OSG:

*“I was newly diagnosed and learned about the low carbohydrates high fats (LCHF) programme from your helpful posts which helped me to set my LCHF diet plan.” (1- Maria)*

*“I was horrified when I was diagnosed a few months ago ... friends told me about the LCHF diet and have been reading about it here thereafter ... this is a great OSG! Thank you all for your posts” (1- Katherine)*

These messages about diet programmes were often posted alongside food recipes, which aided members to prepare healthy meals. Consequently, this helped them avoid eating unhealthy food, which might negatively influence their management of the condition:

*“I’m reading now and learning about different recipes on this OSG that I can prepare and eat during lunch breaks and snacks to avoid eating from fast food restaurants” (I- Bryan)*

*“I have found the recipes on this website truly good. I just change them a bit based on my taste” (I- Andrea)*

*“Many thank all ... I did not know that the lack of salt in my diet might cause the headache I am having. I will keep in mind adding more salt in my food in the future as I am eating less processed food” (I- Jacqueline)*

In addition to fulfilling their diet-related information needs, members of the OSGs also used the platforms to gather information about how and where to find equipment (e.g. blood monitoring tools) and vitamins related to diabetes. For example, I-Mary had an information need related to supplements that help people with T2D. She obtained information about Alpha Lipoic Acid from other members’ positive experiences of using it to reduce blood sugar level and relieve foot pain. Mary purchased it, tried it for a couple of weeks and found that it worked effectively:

*“After reading about the acid here, I have tried it for around three weeks. My blood sugar levels are kind of lower and my feet pain is significantly reduced! ... Thank you, Alexis! I ordered the supplement from the link you provided. It’s much cheaper than the website I found. I have also applied the extra discount you told me about! Many thanks” (I- Mary)*

Other members fulfilled their information needs about specific types of equipment they needed and where to find them by asking other members:

*“Thank you, John and Mary, that’s exactly [a test meter and strips] what I wanted ... I had been reading about different options and was completely confused ... Just ordered what you have suggested. I feel relieved” (I- Riley)*

Besides fulfilling their information needs about diabetes and diet in general, members also expressed how they obtained information from the OSGs about different topics and

techniques they had not known encountered before, such as hypoglycemia, food tracking techniques and how to interpret blood testing results:

*“I am still learning about hypoglycemia. Your post made me understand it more, it now makes more sense for me” (1- Katelyn)*

*“Now I understand what my testing results mean. I found the page you referred me to very helpful. Many thanks!” (2- Phoebe)*

In conclusion, this sub-theme shows that OSGs were used as information sources by their members. Queries might come from people being newly diagnosed and not having experience with diabetes and from people who did not find the information provided by HCPs to be either useful or comprehensive. Many members reported that the information they received from the health care system was not as informative as they expected. They obtained more practical information from the OSGs that helped them to control and manage their condition. For example, a member who was informed that he had T2D but was not provided with any information about the condition. He, therefore, used the OSG to fulfil his information needs about the condition. Another member wanted to know how to evaluate the effect of different types of food on blood sugar levels. She acquired information from the OSG that testing blood glucose levels before and after eating could help her know what food types affect her negatively (e.g., raise their blood sugar to very high levels) and which helped her control her diabetes. Members also obtained information about different perspectives of controversial topics, such as LCHF. The knowledge and experiences exchanged in the OSGs fulfilled some of the members’ information needs. Additionally, members are aware that diabetes is not a static condition and also that what works for a person might not work for another. Therefore, members used the OSGs to navigate through threads and acquire information about different topics to research what could work for them because the information provided by their HCPs might not have been personalised and given to all patients without considering individual differences (e.g., different body reactions to certain

medications, food and activities and different lifestyles). Accessing additional sources to stay informed and gain the knowledge they need to maintain a high level of participation in health care, which are two main components of health care empowerment in the HCE model (Johnson, 2011), shows the high level of engagement of OSG members with their treatment.

The use of the platforms as informational sources also shows the trust that members had in each other. They believe in other members' experience and knowledge even though they lacked medical expertise. Members often stated that they value others' experience more than the knowledge of HCPs', as will be explained in more detail in the following theme. The use of the OSGs as informational sources helped many members to self-manage diabetes successfully and overcome different barriers. The following two sub-themes will explain the consequences of using the platforms as informational sources to fill a gap in members' knowledge.

#### ***4.3.2.1.2 Overcoming Barriers***

The information and emotional support exchanged in the OSGs helped many members to overcome different barriers. The barriers included: poor communication, short visit time, unfulfilled information needs and the use of complex medical language by HCPs. The main difference between this sub-theme and the previous one is that this one indicates that there were some forms of barrier that caused members to use the OSG as a source of information. For example, poor communication between health care providers and patients is a challenge in diabetes care that can result in a lack of information provided by the health care team (S. M. Matthews et al., 2009). Members posted to clearly express how they found the

information they needed in the OSG and which their HCPs did not provide, as explained below:

*“I believe that I was not offered with the information I needed. The leaflet and HCP did not provide the information I needed. I found the information I needed here, after scanning the OSG” (1- Bryan)*

*“I received more personal service here in the OSG more than any HCP I have tried ... I didn't know how little I knew until I joined this OSG” (1- Justin)*

*“This OSG is more helpful than my HCPs” (1- Owen)*

*“I agree, this OSG is way more helpful than HCPs” (1- Luna)*

Others experienced a lack of support from their HCPs (e.g. poor communication, limited appointments) which led them to use the OSG instead to learn about the condition:

*“All information I received about my condition was via this website only ... I barely see my HCPs ... they love to blame me ... all negative things are my fault ... they disagree with all information on this website” (1- Brian)*

*“I have a question about my medications ... where I live there is not much help for diabetes ... it has been over a year since I saw my HCP ... I need to pay to see private health care services” (1- Danielle)*

*“I'm in my late 50s and have been diagnosed 8 months ago ... my HCP simply told me that I have Type 2 and prescribed me metformin without explaining anything about the condition ... I have no idea about the condition ... I have NEVER been provided with the information/support I need ... I'm not an OSG person but using it has a great impact on me” (2- Harry)*

*“When I was diagnosed two months ago, it took me 18 days to see the specialised HCP ... to be honest, this OSG provided me more and much better information than she did” (1- Owen)*

Seeking information from other peers in the OSGs was regularly observed to overcome barriers that resulted from a disagreement on certain topics between HCPs and patients. For example, members shared threads and posts about their meetings with a HCP and how they were disappointed with the discussion and that the meetings were of very limited value. They then asked questions and shared their plans to manage the illness with other members to get their feedback, as explained in the examples below:

*“I was completely unhappy with the meeting! I even had to pay to see him! I was aiming for an interesting conversation about my diet options and physical activities, but he was so narrowed to the*



*system's guidelines. I believe I know better about what works for me, I will carry on with the low-carb diet to control my blood glucose level" (1- Justin)*

*"My HCP laughed at me when I asked her about the possibility that I (and Type two in general) could get a hypo! Even though she prescribed me Empagliflozin whose leaflet clearly states that having hypos is a possible side-effect!" (1- Katelyn)*

*"I had a number of HCPs who told me that I will not get a hypo while I'm taking medications. Well, yes, I do get ... I have learned to trust my judgment over my HCPs" (1- Sarah)*

This is particularly noticeable in controversial topics, such as self-monitoring of blood glucose (SMBG) and low-carb diets. For example, OSGs members expressed how they were not offered the help and information they needed because they mentioned to their HCPs that they were on a low-carb diet or SMBG. This debate and different views on controversial topics were confusing for some members who had just been diagnosed with diabetes and lacked trust in their HCPs. They used the OSGs to acquire the information they needed and to overcome the lack of trust they had towards their HCPs:

*"To be honest, I do not have trust in my HCP, as I knew the problem was with my diet and carb intakes, I started reading on this OSG before seeing him. The first thing he gave me is a pack recommending eating starchy carbs, which in opposition to what members are saying here" (1- Jacqueline)*

*"My HCP's advice to eat two slices of bread every day which led me to this mess!" (1- Owen)*

Other members posted messages to learn about different types of glucose meters and what was the appropriate one for them because their HCPs, believing that they did not need to self-monitor, did not provide them with this information, as explained in the examples below:

*"Thank you, John and Mary! That's exactly what I wanted ... My HCP told me I would not get hypos while taking Metformin, so a meter was not required ... I told them I am planning to get a meter to see how food influences my blood sugar ... I believe it's all about cutting the cost" (1- Riley)*

*"My HCP has been prescribing me test strips ... when I went to the pharmacy today, I discovered that he stopped them ... where can I find the cheapest place to buy them?" (1- Evan)*

*"Went to get test strips today and I was told that I can't get them anymore. What can I do?" (2- Leo)*

*"I think people on the OSG are lucky to learn about self-monitoring because the NHS does not support it ... I feel sorry for the other 3 million people in the UK who have T2D and don't know about it" (1- Ryan)*

OSGs were also used to overcome intrapersonal factors, such as fear. For example, on different occasions members posted about their fear of having low blood sugar level, or of other issues related to diabetes (e.g. not being able to have children in the future). Other members provided the emotional support needed to help members who felt panicked. In the case of having low blood sugar level, for instance, other members tried to calm the person down and explain that it might be a false hypoglycaemic attack, also called a 'hypo'. Other members described the symptoms of the false hypoglycaemic attacks, advised them not to drive and supported the member emotionally to help them overcome this negative feeling. This kind of support had a positive impact on members, as shown in the examples below:

*"I was home by myself only, so that's why maybe I got worried. Thank you all for your advice. Next time, I will not panic" (1- Abigail)*

*"Many thanks to all of you. I really value your support. I feel relieved when I read that's quite normal" (2- Phoebe)*

*"Your posts gave me the courage, self-esteem, hope, support and confidence to overcome my fear" (2- Sofia)*

Emotional support from other peers in the OSGs to overcome negative feelings was highly important during very difficult times. For example, one member expressed their suicidal thoughts and feelings because they were struggling with their health:

*"I feel very bad ... would I die if I injected myself with more than one full insulin pens? Or it would make me cry for help? I have them ready in the fridge! My life is s\*\*t, I feel so low" (2- Imogen)*

Other members supported the member emotionally and urged them to contact a specialised support service for people who have suicidal thoughts:

*"I'm very sorry to hear you are having this feeling. Do you have a person you can talk to? You can talk to the Samaritans if you don't [page link]. You can contact them by phone or email (hugs)" (2- Logan)*

*“Please contact any person who can help you. If you believe you are going to commit suicide or hurt yourself, please get in touch with your crisis team and the Samaritans then please head to the emergency department. Keep posting here, we can offer support (hugs)” (2- Amelia)*

2- Imogen responded after an hour and shared her unsuccessful attempt to get the help she needed from a mental health service:

*“I contacted my community mental health team and they told me that I was discharged back to my GP a few months ago! I told them I did not receive a letter about that and I had been with them for many years. I wanted to speak to the person in charge as I am feeling suicidal and the receptionist refused and referred me to contact my GP! I said I cannot contact them now just for a chat! She said that they are not an emergency service, which made me cry!” (2- Imogen)*

Other members continued to offer emotional support and urged Imogen to contact anyone who could help:

*“Sorry, you are feeling down. Please contact anyone who can help.” (2- Maya)*

*“You are not alone, get in touch with Samaritans and talk with them about your suicidal thoughts and feelings. They offer 24/7 helpline at [Samaritans’ telephone number]. It is disappointing that CMHT did not offer the support you need” (2- Harper)*

*“I was in this position a number of times. Just think about all people you love; we are here for you whenever you want” (2- Evie)*

Imogen replied after a couple of hours thanking them for their support:

*“Thank you all for your support! I have received the care I need, I’m safe now ... I did not think that many people would care about me. That gave me food for thought. Many thanks for asking about me” (2- Imogen)*

Another member expressed their feelings about their addiction to sugar and carbohydrates and how that resulted in negative diabetes management. The member expressed their attempts to decrease the amount of sugar intake. However, they were still afraid of the future because of their addiction to sugar. Other members shared techniques to reduce sugar intake and their experience with the member and assure them that this fear could be overcome. After

12 months, the member reported, in the same thread, their success in removing sugar from their diet:

*“It has been 12 months and I am free from sugar today ... I have lost weight too ... my blood sugar is never high ... my HbA1c is in the normal range” (1- Tracy)*

Tracy, in this example, feared having a relapse after cutting sugar from her diet. She and other members compared sugar to alcohol or heroin and described it as an ‘addiction’. They shared their previous attempts to reduce their sugar and carbohydrate intake which lasted for a long period of time. Tracy, for example, had previously tried to cut sugar but she relapsed after a year. She was, therefore, afraid to repeat the same scenario again with further (unsuccessful) attempts. The OSG, therefore, was an important source of support for her to reach her goal. She updated the thread occasionally and received support and encouragement from other members. OSGs, in this instance, served as a source of emotional support that helped members to overcome strong fears.

In summary, OSGs were found to offer support to members with T2D to overcome various barriers including these related to HCPs and intrapersonal factors. Members were found to seek information from the online communities when there was a lack of information from HCPs, poor communication, a long waiting time, disagreement and a lack of trust.

Additionally, they used the platforms to cope with fear and anxiety, which were partly caused by having diabetes. This sub-theme shows how their use of OSGs was helpful to overcome different barriers and problems, some of which were extreme. Other members’ knowledge, experience and support assisted members to cope with different difficulties, making OSGs a valuable source of support. Being well informed about diabetes and overcoming barriers

resulted in good control and management of the condition, as explained in the next sub-theme.

#### ***4.3.2.1.3 Control and Management of the Condition***

In this sub-theme, members expressed how the knowledge and support obtained from OSGs helped them control the illness in general. The word ‘control’ here refers to the daily blood glucose checking whereas ‘management’ refers to the long-term overall attempt to maintain a healthy lifestyle and their diabetes is checked regularly. To manage the condition successfully over time, a person needs to adopt a healthy lifestyle and change behaviours in terms of physical activities, eating habits, medications, setting and achieving realistic plans, knowing possible barriers, etc.. In this sub-theme, members of the OSGs expressed how the use of the OSGs helped them achieve day-to-day control and overall management of the condition or introduced them to techniques, skills that helped them to do this. For example, members expressed how the information and support they received from OSGs helped them to manage the overall aspects of their condition:

*“I love this OSG, over the past few years, it helped me to control my diabetes” (1- Sydney)*

*“We are lucky enough to belong to this community which has useful information and experiences that help us to manage diabetes” (1- Daniel)*

*“My HbA1c dropped from 11 to 6 in six months. Many thanks to this OSG. I have been a silent member and learned a lot from all of you. I will try to contribute with my experience” (1- Henry)*

*“The education I received herein the OSG, especially about LC, helped me to bring down my HbA1c from 54 to 31 and lose 28 kg... without the information I found here, I would have followed a completely different path!” (1- Thomas)*

More precisely, members learned about specific skills and techniques that helped them to control the condition. For example, members learned from their peers on the OSGs about the importance of keeping records of test results and food intakes. Heisler, Piette, Spencer, Kieffer and Vijan (2005) associated patients’ knowledge of past test results with a better self-

management of diabetes. Keeping a record and being aware of test results and daily food intake are recommended long-term practices for people with diabetes to manage the condition effectively (Diabetes UK, n.d.-a). Members on the OSGs advised others repeatedly to adopt such techniques to control the condition. Members who received the advice, reported on their adoption of the techniques, as explained in the examples below:

*“I understand that I should have kept a record of my test results. However, I was kind of confused and did not have a clear plan. Thank you for your advice here, I will ask to have printouts after each test and keep them. I did not know that I can do that before! I have also bought a diary to keep tracking my diet” (1- Bryan)*

*“Thank you 1- Christian for your advice about keeping a food diary which I read when I was diagnosed. I have followed the advice and it has a dramatic change in my health! I wish I have started it years ago!” (1- Katelyn)*

*“I have started a food diary after reading your comments ... I now realise it is very important ... I think my meals going to be healthier” (1- Hayley)*

*“I now understand what caused the spike in my blood sugar level. As you recommended, I went through what I had eaten during the last few months and I think it’s all because of the fast food I eat for lunch, due to my work nature. As Sean recommended, I will have a plan to control that and take care of what I am eating” (1- Bryan)*

While there is some debate around whether SMBG is useful for people with T2D or not (Clar et al., 2010; Farmer et al., 2007), the guidelines from the National Institute for Health and Care Excellence (NICE) in the UK do not, generally, recommend HCPs to advise patients to self-monitor their blood glucose levels except in a few circumstances (e.g., if the patient is taking insulin or is pregnant) (NICE, 2017). This debate was also largely present in the OSGs. However, the majority of members believed that SMBG was essential to effectively manage the condition; therefore, they advised others to self-monitor even though their HCPs did not advise them to do so. For instance, members who were advised to self-monitor reported a positive improvement in the overall management of their condition:

*“It has been a month of having the meter. It has been a great improvement in my blood sugar! For those who are new in diabetes: members here ARE RIGHT! You MUST have a meter to adjust your diet and sugar level” (2- Jacob)*

*“On advice on this OSG, I bought a meter. It’s really helping me to control my diet” (2- Isabella)*

*“My HCP advised me not to self-test and just do the quarterly HbA1c tests. When I joined the OSG I was highly advised to test which I did and has been the best advice I received which helped me to control my diet” (2- Isla)*

*“Thank you for your advice [to self- monitor] ... I found it a very helpful tool to manage my diet” (1- Samuel)*

*“Thank you for your advice! I have been given a monitor and my medication has been changed. It feels much better” (2- Charlotte)*

Similarly, members learned about different diet options which resulted in better management of their condition as explained below:

*“Since following the LCHF diet [which I learned about here], I have lost weight and reduced my haemoglobin level! Will keep following the diet programme to lose more weight and be in the normal, controlled, range” (1- Katherine)*

*“It has been a few weeks since started the Newcastle diet. My weight and sugar level have greatly decreased” (1- Angelina)*

*“Due to the LC advice given here, my average blood sugar level is much better” (2- Jacob)*

*“I’m glad that I decided to do the LC. It obviously has a positive impact on me” (1- Jacqueline)*

*“After learning about LCHF from you folks, I am happy to tell you that my test readings and weight are going down and I feel much better. Thank you all!” (1- Maria)*

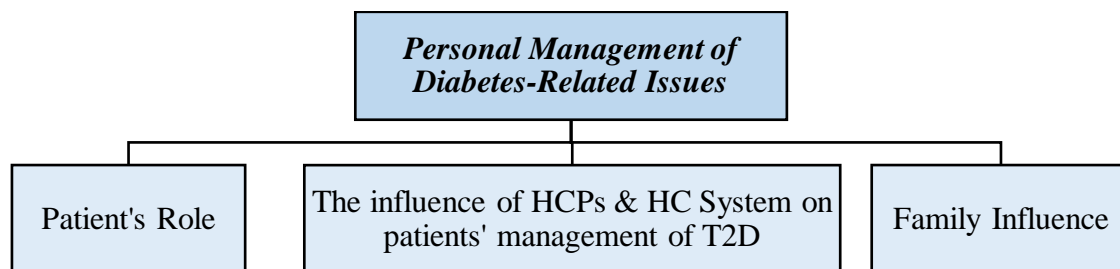
*“A few years ago, I was diagnosed as a pre-diabetic. As I’m taking a medication for another condition, it changed my diet habits and resulted in my blood sugar to be in the diabetic range. So, I decided to alter my eating habits and found very useful information about LCHF in this OSG which I followed. Now, I’m back to the pre-diabetic range!” (1- Paige)*

This sub-theme shows how the knowledge and support exchanged in OSGs might contribute to better control and management of diabetes. While some members explicitly reported the pieces of information they learned from OSGs that helped them to control and manage the condition (e.g. learning about diet options), others referred to the overall knowledge and support obtained from the OSGs. However, overall, the information and support obtained from OSGs helped members to learn more about the condition and overcome different barriers which resulted in better control and management of the condition. Members were not aware of the information they received on the OSGs either because their HCPs did not agree with the advice or had not received such information elsewhere. Therefore, exchanging

experiences among members across the OSGs allowed some members to learn skills and acquire knowledge that is useful to control diabetes.

#### **4.3.2.2 Personal Management of Diabetes-Related Issues**

This theme contains threads/posts that discuss topics that influence the general management of the condition (as shown in Figure 4.4).



**Figure 4.4 Subthemes of the theme: Diabetes Management**

##### **4.3.2.2.1 Patient's Role**

In this sub-theme, members repeatedly highlighted the importance of being active patients. They expressed their belief that taking medications alone was not the right way to solve the problems they faced. Instead, being engaged and looking for different options was considered the optimal approach to cope with the condition. For example, members encouraged a person who had a negative HbA1c result to engage with, and be active in, the management of the condition:

*“if you don't engage with your diabetes you will end up having more medications and complications ... it can be self-managed if you engage and be aware and it's unexpectedly easy and empowering to do so ... it's the time to do more actions: get monitoring and keep food diary ... you have the help, information and support you need here” (1- Katelyn)*

Some OSG members emphasised that they wanted to be in control of their condition and not just follow instructions from their HCP. This became more prominent when there was



disagreement between the members and their HCP team. This type of patients believed that their HCPs were a source of support that they could consult and not just follow blindly, as explained in the examples below:

*“I told my HCP that I’m on this OSG and I follow LCHF ... I hope she realised that I want to take control of my condition” (1- Alexander)*

*“I want a testing meter ... I want to be in control” (1- Riley)*

*“My HCP informed me that he was there to advise me only, and it’s my decision to follow his advice or not ... I went against his advice in self-testing and it made a positive impact on me ... we are different, do what’s right for you ... it’s your decision, not anyone else’s” (1- Ashley)*

However, other members showed a lack of trust in their HCPs and felt responsible to take full control of their diabetes without the support of their HCP team:

*“I don’t discuss my diabetes with my HCPs. They only see my yearly HbA1c and tell me to continue doing whatever I’m currently doing. I like it this way! I like managing things myself ... it’s my condition, I do it on my own way” (2- Ava)*

*“You have to convince your partner and explain that your HCP has been trained many years ago, you have the right to make your own decision and take control ... according to my HCP, what we have achieved here is impossible ... we are all expected to get worse and end up on insulin” (1- Andrew)*

*“I don’t expect my HCP to know everything about diabetes! We all need to be experts in our own conditions because we all MUST treat our own condition ... that’s why this OSG is here for ... to encourage us to be experts in our diabetes” (2- Sophia)*

Other members highlighted the fact that diabetes can be treated not only through medications. They explained that different people have reactions to certain medications, specific foods and physical activities. Therefore, patients have to be active and find what works for them by themselves, as explained in the following examples:

*“I think understanding that there is no one size fits all people with T2D is essential ... we have to make individual choices” (1- Mackenzie)*

*“We all are fully different people, you need to understand what works for you” (1- Ashley)*

*“It’s MY OWN diabetes, therefore, I have to take care of it myself, no one else can do it for me” (1- Andrew)*

*“We all different, what works for you might not work for me ... there is no quick way to fix my condition, if I want positive results I need to make good decisions, it’s all up to me ... that what I have learned” (1- Margaret)*

*“I think we need to use all sources available, including this OSG, to learn what works for us” (2-Emily)*

*“I can’t believe how unaware some people with diabetes are ... they rely on a magical pill and believe it would all necessary to cure their diabetes in the future” (1- Austin)*

The involvement and engagement of patients with their diabetes appeared to result in better management of the condition. As shown in the examples below, being active and making informed decisions helped some patients control their conditions effectively:

*“My dad has T2D for 30 years. We basically followed the general instruction. It was bad, chronic and progressive. For me, it’s completely different. With the knowledge available, I’m able to control it myself” (1- Brandon)*

*“After having a high HbA1c, my HCP decided to put me on Metformin which made me struggle ... I decided to stop taking it and try the diet. I’m happy today to be in the pre-diabetic range” (3- Lily)*

Empowered patients tend to access additional resources to know their legal rights and keep a high level of participation in care (Johnson, 2011). Members on these OSGs exchanged knowledge and experience about their legal rights, which showed a high level of engagement with their care. For example, when a member posted a thread to ask about what they could do when their pharmacist stopped their testing strip prescription and informed them that they would not be able to be prescribed testing strips again, member 2- Isla shared their experience and informed the member about their legal rights. 2- Isla explained the guidelines issued by NICE to the member and then demonstrated how they managed to contact the Clinical Commissioning Groups (CCGs) and ask for their legal rights:

*“I could not financially support my testing strips anymore, I went through the NICE guidelines in details and, with the help of my HCP, I wrote to the CCG explaining my justifications ... My HCP was then able to prescribe me testing strips again ... I can share the letter I wrote if anyone wants to use it” (2- Isla)*

Similarly, 1- Mackenzie posted to another member whose testing strip prescription had been stopped to make them aware of their legal rights:

*“You should write to your HCP, quoting the following NICE guidelines ... you should ask if it is CCG, HCPs or staff who chose to ignore the NICE guidelines” (1- Mackenzie)*

Another member posted to advertise a campaign to challenge NHS from limiting test strip prescriptions:

*“We are now challenging this action through this campaign [link to the campaign’s page], you can also find on the page information about how to get this decision changed” (2- Sara)*

These examples show how some members used all sources available to know about and enforce their legal rights. The use of OSGs as platforms to exchange knowledge and experience helped to spread this culture. It allowed members to be informed about their rights and to be engaged in the management of the condition.

Diabetes self-management education has been associated with significant improvements in care for people with T2D (Chai et al., 2018). Members highlighted the role of being well informed in allowing them to be active and in control. From what Chai et al. indicated, being well informed about the condition is the responsibility of patients and allows them to make informed decisions:

*“I think education comes first for people with diabetes... even if HCPs are too busy to educate, they can refer patients into educating themselves so they can make informed decisions” (1- Madeline)*

*“You need an HCP who listens to you, you have to be fully informed of what you have to do to have a good control” (1- Zachary)*

This sub-theme shows how members expressed their intention to take an active position in the management of their condition and encouraged others to do so. They explained that the condition was not static and different people had different reactions to it. Each individual was therefore required to navigate through different medications, diets and physical activities to find what was good for them. This shows the level of awareness these patients had. Members also showed how they used all sources available to know their rights and be active in

enforcing them. This sub-theme also demonstrates the level of participation of some members in their care. The use of OSGs helps to spread this culture. It makes other patients aware of the condition they are having, their rights and their role to manage the condition. Further discussions about the role of patient involvement and expert patients are presented in Sections 4.4.5 and 4.4.6.

#### ***4.3.2.2.2 The influence of HCPs & HC System on patients' management of T2D***

This sub-theme illustrates how HCPs, the health care system and its guidelines affected the management of diabetes for OSG members. There are some guidelines from the authorities in the UK, such as the NICE (2017) guidelines regarding blood glucose meter or strip prescriptions and the NHS (2016b) position towards carbohydrates in the diet, to direct medical practice. These guidelines might limit HCPs from performing some actions or force them to take a specific position. When there is a disagreement between HCPs and patients because of guidelines (or just because of having different opinions), the perceived reactions of HCPs varied. Some of them showed support even though they disagreed with the patient, as in the examples below:

*“I’m lucky to have my HCP. Although she strictly follows the NHS guidelines, she is open-minded and accepts my choices even when they are against hers. She works WITH me and supports me when anything goes wrong ... she is happy that I found my own way” (I- Katelyn)*

*“I think, and as my HCP told me, it’s my health and my duty to take care of it. Either I follow his advice or not, he is only there to provide it and it’s my decision what to do” (I- Ashley)*

In this type of relationship, the HCP worked with the patient as a team, advising them and supporting their decision regardless of whether they agreed with it or not. As outlined in Section 2.7.4.2, Mohanty (2017) described this relationship as a “mutuality relationship”, in which both the patient and the HCP have equal involvement in the meeting and they are both

considered experts. In contrast, in the following example, the HCP did not expect the patient to be involved in the meeting and saw themselves as the only experts in the relationship:

*“The medication that my HCP gave me limited my physical activities. So, I told him to reduce it and he just ignored me! I told him that people on this OSG suggested me to buy a meter; he told me not to take advice from unqualified people! I told him these people cope with the condition every day not learn about it from the book! He doesn’t even listen!” (2- Millie)*

In this paternalistic relationship, the HCP exerted a high level of control in deciding what the patient should do and believe in (Mohanty, 2017). This type of relationship limits the involvement of the patient in their own care. It makes patients see their HCPs as their bosses, not partners, therefore, they might hide some facts when they go against their HCPs’ opinion. Some OSG members felt that this relationship is the result of the passive position of most people with T2D, who preferred to be inactive and just took their medications and followed instructions without participating in their care, as illustrated below:

*“I agree with Jose, most HCPs don’t anticipate patients to be active in their care. Most patients are happy to relax and take the medications and continue doing whatever they were doing” (1- Sarah)*

*“Keep in mind, most HCPs see patients with T2D who claim to follow a healthy diet but in fact, they are not ... their T2D is not well controlled” (1- Jose)*

A member, who was also a clinician, agreed that HCPs do not have the time to research different treatment options and styles:

*“Health care is supposed to be patient-centred and personalised ... this is NICE’s responsibility ... we, as HCPs, are too busy to find out what the best practice is” (1- Jada)*

Other members questioned the health care system because of its position regarding the optimal diet system which advises people, including people with T2D, to eat starch and carbohydrates, as well as protein, fruit and vegetables:

*“[after reporting a positive result] I wonder what the results would have been if I followed the NHS advice (eat starch and carbs)! ... the first thing they tell you is to eat carbs and starch!” (2- Jacob)*

Others, however, questioned the process of prescribing test strips and the role of different HCPs and health care authorities:

*“Most people with diabetes believe that HCPs are wrong when not prescribing test strips ... it doesn't save NHS' money, it costs them more in the future because of the complications” (2- Oscar)*

*“I believe that local CCGs have a very narrowed interpretation of NICE guidelines ... if your GP prescribed you test strip why would the pharmacist stop that? Does he have access to your medical records?” (2- Isla)*

A member who was also a nurse explained that some HCPs have more flexibility than others when it comes to following guidelines:

*“As a nurse who has T2D, we are restricted by the NICE guidelines, otherwise, we would lose our jobs. NICE guidelines prevent GPs from prescribing test strips, however, GPs have more flexibility than we do, so they can go around and prescribe them” (1- Jada)*

This and the previous sub-theme show the difficulties patients could face when they had a different approach to control and manage their condition than the one suggested by their HCPs and this led to a tension with their HCPs. Lack of communication between different HCPs was reported to be confusing by a number of members:

*“Within one hour, I have received conflicting advice from my HCPs which is fully unacceptable” (2- Isabella)*

This repeated lack of communication led OSG moderators to take action and organise a campaign that aims to make HCPs and the HC system aware of this problem and offer solutions to reduce it:

*“It's sad to receive different information. That's why we campaigning to minimise the lack of communication between HCPs” (2- Rosie)*

This sub-theme explored the influence of HCPs and the HC system on the management of diabetes by OSG members. HCPs, as well as the HC system, play an essential role in empowering or disempowering people with diabetes. The type of relationship that HCPs establish largely affects patients' degree of involvement in their care. On the other hand,

members reported that HCPs mostly saw patients who were not willing to be involved in the management of the condition, which made them take the same position also with patients who were willing to take an active part. The HC system instructs HCPs to adopt patient-centred relationships, however, members in this sub-theme explained some barriers that prevented HCPs from adopting it. Section 4.4.4 presents a discussion about the doctor-patient relationship.

#### **4.3.2.2.3 Family Influence**

This sub-theme describes how close family ties can influence and contribute to the management of diabetes. Members, for instance, shared their concerns about how their partners supported the opinion of HCPs over theirs or did not agree with them on the way they manage their condition, as illustrated in the examples below:

*“My spouse thinks I should not self-test or count my carbs intakes. He just wants me to lie back and take my increased medication and follow precisely what my HCP told me without even changing my unhealthy diet ... because I’m learning from your experiences, he is concerned that I’m against the medical advice and taking advice from the Internet and unqualified people” (1- Samantha)*

*“My partner had the same worries, but the good thing that he knows our GP is unknowledgeable” (1- Sarah)*

*“My spouse believes I’m hypochondriac because I self-test my blood sugar which he is against” (1- Abigail)*

*“It’s difficult to get your spouse and family members on your side when managing your diabetes because diabetes is hard to understand” (1- Nicholas)*

On the other hand, on various occasions members highlighted the importance of the support and help they receive from their partners and family, as shown in the following examples:

*“My partner is so supportive ... he goes with me to the HCP and asks very important questions ... he organises my medications for me which is very important” (2- Scarlett)*

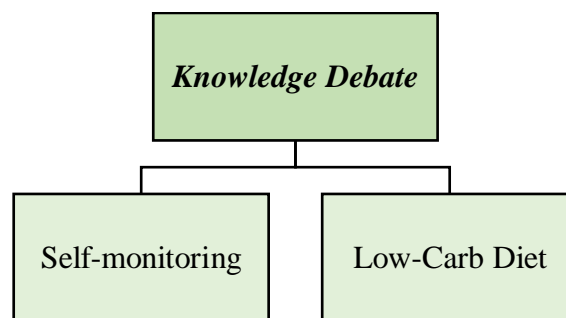
*“My family members are very supportive” (1- Autumn)*

*“I thought my family members would laugh when they know about what I did to lose weight at this old age, but they were very supportive” (3- Lilly)*

This sub-theme shows positive and negative emotions members had towards their family's opinions on their management of diabetes. The social environment has a direct effect on peoples' health care empowerment in the HCE model (Johnson, 2011). Additionally, within the Health Belief Model, social factors, including social groups, have an indirect influence on people's health behaviours by directly influencing the perceived benefits and barriers of the health action and seriousness and susceptibility of the disease or its consequences. Therefore, partners and family members play an important role in influencing the management of diabetes for people with T2D. More discussion about the role of family support is presented in Section 4.4.9.

#### ***4.3.2.3 Knowledge Debate***

This theme highlights members' discussion regarding controversial knowledge-related topics. It consists of two sub-themes that represent the most controversial topics presented in the data as shown in Figure 4.5 below.



**Figure 4.5 Subthemes of the theme: Knowledge Debate**

##### ***4.3.2.3.1 Self-monitoring***

In this sub-theme, members exchanged their opinions about SMBG levels, also known as self-testing and home testing, and their views regarding the position of HCPs and the health care system. In general, NICE (2017) does not advise doctors to offer SMBG unless the patient is on insulin, on oral medication that might increase their hypoglycaemia, is pregnant



or planning to become pregnant or if there are signs of hypoglycaemic episodes. Members on the OSGs occasionally referred to the guidelines and discussed how their HCPs applied them. A number of members, for example, reported that they had a disagreement with their HCPs because they restricted the prescription of blood sugar meters and testing-strips even though they were eligible according to the guidelines:

*“Although I’m on three medications that lower my blood sugar level, my HCP took me off test-strips. It’s very concerning” (1- Sara)*

*“It is very infrequent for an HCP to go against the guidelines ... even though you are insulin dependent you have to prove that a hypo event has occurred to you while you are on this medication” (1- Ryan)*

Members expressed their frustration at being limited from self-testing their blood sugar levels and their disagreement with the guidelines. They wondered how they would manage the condition, if they were not able to know their blood sugar levels, as illustrated in the examples below:

*“How I’m supposed to know how different foods affect my blood sugar levels if I don’t test?” (1- Riley)*

*“I was told that my blood sugar level is low ... how would I know that I am low if I’m not testing?!” (1- Abigail)*

*“I’m still surprised that the NHS doesn’t see the importance of testing for people with T2D” (1- Katelyn)*

When a member talked about their disagreement with their HCPs because they refused to prescribe them meters and strips, many members responded by highlighting the value of SMBG and how that positively impacted on the management of their diabetes, even though HCPs did not see such value. They expressed their beliefs that SMBG was a very helpful practice and HCPs limit it by not prescribing meters and test strips. For example:

*“I was advised by many HCPs, not to self-test. However, after joining the OSG, I started to test which had a great impact on the management of my diabetes” (2- Isla)*

*“I believe keeping records of meter readings, as well as food intakes and medication, has extremely helped me to see how different things impacted on my blood sugar levels” (1- Gavin)*

*“If there is one thing I would recommend [to members who just was diagnosed with T2D] is to self-test ... unfortunately, you can't trust HCPs who appear to believe the system” (1- Jesus)*

*“self-testing is essential for me to understand what I need” (1- Ashley)*

*“My advice is to get a meter after the diagnose and adjust your eating to it” (1- Owen)*

*“I was asked not to self-test because it's not necessary for T2D and I might become obsessed with testing. However, I still get asked what my readings were! ... do whatever you can do to get control. I sometimes test to see how certain meals affect me” (1- Sophia)*

Others, however, thought that the primary reason why the NHS and HCPs limited SMBG was to reduce costs, as explained in the examples below:

*“It's all about money ... the practice wants to save some £££” (1- Mackenzie)*

*“The budget spent on testing strips can be easily reduced as the NHS views it as an easy category to cut costs” (2- Muhammad)*

*“My HCP did not agree to prescribe me a meter. I believe it's all about the cuts” (1- Riley)*

*“In the long term, preventing patients from home testing might cause more complications which costs the NHS more to treat in the future.” (2- Oscar)*

Since this topic is controversial, some members reported their confusion because they received conflicting advice about whether they should self-test or not:

*“When I called 111<sup>3</sup> they told me I should self-test four times a day ... a few minutes later when I went to the doctor, they told me I should not be self-testing because it's a waste of time!” (2- Leo)*

*“Within one hour, I received conflicting instructions (not advice) about self- monitoring from my HCPs which is fully unacceptable” (2- Isabella)*

*“Do a test, do not test ... I was given Gliclazide that I did not want to take which dropped my sugar level to 2 ... I asked my HCP for a meter, but they refused because I don't need one!” (2- Charlie)*

According to OSGs members, limiting blood sugar meters and test-strip prescriptions was a new practice within the NHS. They reported that, in the past, the practice was to support self-

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<sup>3</sup> This is the telephone number of the information/advice service provided by the NHS in England.

monitoring and blood-glucose meters and strips were easily prescribed to diabetes patients, as explained in the following examples:

*“When giving meters and testing strips for people with T2D were trendy, my HCP urged me to test because he thought not testing is like driving without looking at the speedometer” (2- Ruby)*

*“Previously, at one point, it was the tradition to give people with T2D a meter and test strips, so they could be able to notice how different foods influenced them. Unfortunately, it’s not the same anymore” (2- Freya)*

Because of the confusion, disagreement, frustration and disappointment members with T2D expressed in the OSG, DUK started a campaign to express the voice of people with T2D. The campaign is meant to lead the NHS to revise their policy towards self-monitoring prescriptions. OSG moderators occasionally referred to the campaign’s main page to make members aware of it and to allow them to participate in the campaign.

This sub-theme shows the position of NICE and the NHS regarding SMBG, how HCPs implemented the guidelines from the perspective of OSG members and how members perceived the position. As explained above, members highlighted the value of self-testing and how the NHS hinders them from taking control of their diabetes by not prescribing blood-glucose meters and testing strips. Although they met the guidelines, some members faced difficulties in getting prescriptions for blood-glucose meters and testing strips. Many members believed that the system limited SMBG for people with T2D to reduce the financial cost to the NHS budget and not because testing was not beneficial. This shows how policies implemented by the health care system may present a challenge for people with T2D. These policies might also create a tension between patients and HCPs. Further discussion about the role of these policies is presented in Section 4.4.2.

#### 4.3.2.3.2 Low-Carb Diet

Low carbohydrate diet was another controversial topic among people with T2D and their health care providers. This sub-theme captures the members' opinions about different low carb diet programmes and how their health care providers viewed such programmes. Many members reported negative reactions from their HCPs when they knew that they followed low carbohydrates diet programmes, as explained in the examples below:

*“When I told my dietician that I’m on LCHF diet, she looked at me strangely! Then she advised me not to go on a low carb diet and follow the NHS Eat Well plate because it is a great diet, she continually repeated that! I agreed to change my diet but in fact, I will not, it is a fast way to poison yourself with sugar, I’m happy with LCHF” (I- Alexander)*

*“Similar to I- Alexander, I had the same with my HCPs. Therefore, I started to communicate with my HCPs differently. I nod, smile and say thank you then ignore everything they have said” (I- John)*

*“My advice when dealing with HCPs regarding low carb: make the alterations without informing them at the beginning, keep a diary of your readings and give them the readings and the fact after they review your bloodwork” (I- Mackenzie)*

*“My HCP became very angry when I told them that I’m on a low-carb diet” (I- Elizabeth)*

Although many members reported that they had a disagreement with their HCPs about low-carbohydrates diet programmes, they assured others that the programmes helped them to control their diabetes:

*“For 4 years, I controlled my diabetes through low carb diet” (I- Sydney)*

*“My HCP was surprised when knew that I’m on LCHF although I had good test results. We agreed to continue on the diet for 4 months. After 4 months, I had really good results. Then, she said: low carb is the best way to manage diabetes for all patients but it’s hard, so I don’t expect all of them to continue on doing it.” (I- Mackenzie)*

Other members were not sure about the amount of carbohydrates intake the low-carb diet involved. Since the majority learned about low-carb diets from the OSGs, they used the platforms to know and adjust the amount of carbohydrate intake, as shown in the examples below:

*“I am not sure how low [carb] should I go ... I am aiming to eat 30grams per meal” (I- Lauren)*

*“I started with 30-40g for more than two years. Now, I eat nearly 40-50g a day.” (I- Ava)*

*“Some people consider 30g per meal as too much, for myself, I’m trying to have less than 20g per day and it works for me” (I- Timothy)*

*“The best answer to how high/low we should go is to use your meter to know how food affects you” (I- Kayla)*

*“My body reacted positively to 70g per day. My advice is to start simple and adjust accordingly” (I- David)*

Members exchanged their experiences about the amount of carbohydrate intake in their diets, while others used the OSGs to learn more about the nature of the low-carbohydrate diet programmes. This might be because the OSGs were their first source of information regarding low-carbohydrate diet. This might also be because they were not able to ask their HCPs about this type of diet programme.

While the LCHF programme advises people with T2D to decrease the carbohydrate intake and increase fat consumption (Noakes, 2013), Eatwell Guide, the NHS diet guideline, recommends that all people, even those with diabetes, should eat a balanced diet that includes fruit, vegetables, starchy carbohydrates, dairy and proteins (NHS, 2016b). The guide recommends a daily intake of at least 30% of starchy carbohydrates per person. A number of members consistently repeated that the diet programme promoted by the NHS and HCPs did not work for them. They believed that the NHS diet advises people with T2D to eat carbohydrates, which they think is not healthy for them:

*“The diet that HCPs advised me to follow is completely wrong for me. My blood sugar levels would be high if I followed the guidelines, I received during the diabetes education course. LCHF works for me” (I- Elizabeth)*

*“I would imagine the advice your HCP gave you is to follow the usual ‘healthy’ (nonsense) diet. If your HCP think jacket potatoes are good for people with T2D then she is talking nonsense. Many of us on this OSG try to minimise carb, if not avoiding it” (I- Gavin)*

Many members reported that one of the key information points they learned when they discovered low-carbohydrate diets was that carbohydrates convert into sugars. This information about carbohydrates changed their approach to food and resulted in better management of the condition:

*“The most important thing I have learned is that carbs become sugar! So I eat less carb” (I- Ellie)*

*“I did not know that carbs become sugar. When I knew, it changed the way I looked at food. It is the most important thing I learned” (I- Gavin)*

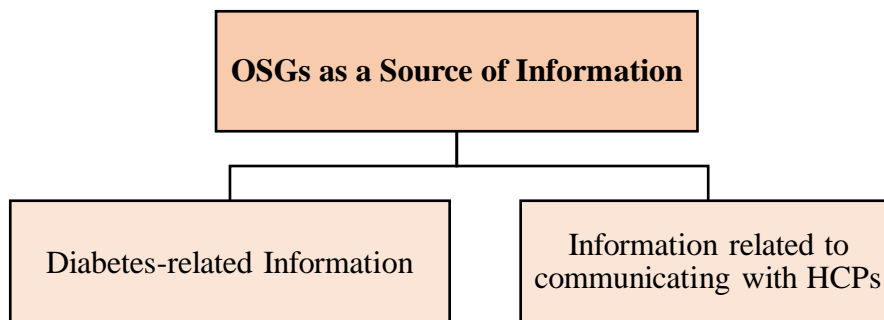
*“I did not think about carbs as sugar! I believe most people would find it challenging to understand that carbs (rice, bread, pasta, etc.) are not safe options” (I- Ian)*

In conclusion, this sub-theme shows how low-carb diet programmes were perceived by OSG members and HCPs. It explains the disagreement between members and HCPs about the programmes. While the NHS advises people with T2D to follow a balanced diet which includes starchy carbohydrates, many members believed that such diet was not appropriate for people with T2D. They experienced bad results when they followed the NHS-recommended diet. Many reported that, when they knew that carbohydrates convert into sugar, it changed the way they looked at food. They believed their reduction of carbohydrates was the key to control their diabetes. The disagreement between members, their HCPs and the NHS about low-carb diets might have resulted in distrust between some members and the health care system. Many members reported that they changed the way they communicate with their HCPs who did not support their choice to follow a low-carbohydrate diet. Others reported that the health care system did not support low-carbohydrate diets because they were not supported by scientific evidence. Patients, however, did not want to wait years for a study that supported the low-carbohydrate diet so that the HC system could change their perspective. They valued their positive experience when following a low-carb diet over the advice from their HCPs. This, as a result, shows how the discussions on the OSGs support patients to be more independent of their HCPs and adopt choices related to the management

of their condition regardless of the agreement of their care providers. Being independent patient created tension between the patient HCPs. Section 4.4.2 presents how the conflicting information was presented for people with T2D and Section 4.4.4 discusses the result of this on the patient-doctor relationship.

#### ***4.3.2.4 OSGs as a Source of Information***

This theme shows how members used the OSGs to seek and share information about diabetes-related issues, coping with HCPs.



**Figure 4.6 Subthemes of the theme: OSGs as a Source of Information**

##### ***4.3.2.4.1 Diabetes-related Information***

This sub-theme had a higher proportion of data than any of the other sub-themes identified. It includes all types of questions and answers that seek to understand diabetes and other aspects related to diabetes. One of the most common topics members used the OSGs to seek and share information about was nutrition. Members often asked their peers what they should eat and avoid and the products/dishes they recommended. Members exchanged their experiences about diets and different food items and how they influenced their blood sugar levels and how, in general, their body reacted to certain food items and diets, as shown in the examples below:

*“Should I eat carrots or avoid eating them?” (1- Tracy)*

*“Is there an acceptable sugar content range on the packaging?” (1- Aidan)*

*“I aim to stick to berries and reduce apples ... I heard bananas are not good, so I stopped them” (2- Harper)*

*“Bread and bananas raise my blood sugar levels” (1- Elizabeth)*

*“What do you guys have for breakfast?” (1- Aidan)*

*“I usually have eggs, cheese, yoghurt, berries and coffee and cream for breakfast” (1- Caroline)*

Another topic that members widely used the OSGs to seek and share information about was blood sugar level test results and understanding their meaning. Members reported their body status, the food they ate and their recent blood sugar test and asked different questions such as:

*“Is 4.3 too low? I tested an hour ago, I felt unstable and shaky. I had not eaten anything since last night when I tested. I ate peanut butter and I feel better now” (1- Abigail)*

*“My blood sugar level is 3.2 after two hours from having a meal, is that normal?” (1- Chloe)*

*“My blood sugar levels average for 14 days is 9.1, is it good?” (2- Jacob)*

*“I’m newly diagnosed, on Metformin three times a day, my blood sugar level is 14.3; I know it should be between 4 to 7 right? Do I need my blood sugar level to be always under 7.8 after meals?” (1- Jacqueline)*

*“My blood sugar reading was 3.8 two hours from having tea, not sure why?” (1- Alexandra)*

In addition, members used the OSGs to exchange their experiences about using different types of self-monitoring devices. Experienced members provided others with a review of the available devices and their advantages and disadvantages. Members sought, and were provided with, information about the most economical way to find self-monitoring devices and strips. They exchanged external links to stores that sell the devices and strips, as explained below:

*“Where can I find the cheapest place to buy Tee2 strips?” (1- Evan)*

*“This store sells the meter in a very good price [link to the store website]; remember to check the box that says you are diabetic, so you don’t have to pay VAT” (1- John)*



*“SD Codefee is the cheapest meter and is used by many of us here. You can find it at [name of store]”  
(2- George)*

Another topic of information seeking was medications. Members asked and exchanged information about different types of medications with their peers, the reaction of their bodies towards them and the alternatives to some medications, as shown in the examples below:

*“I have been prescribed Metformin a couple of weeks ago but my body did not react to it well. They, therefore, changed it to Gliclazide. I’m also on other couple medications. Do I need to test? [I] need [your] advice” (2- Charlotte)*

*“Metformin made me feel lazy and not be able to leave the house. My HCP changed it to Suktarto which is kinder” (2- Jessica)*

*“Metformin was originally developed as a weight loss drug. Carbs, therefore, will not be absorbed by the stomach” (3- Emma)*

Additionally, members exchanged other information, ranging from information about software that is used to help people with diabetes, insurance providers, to legal issues and others, as demonstrated in the following examples:

*“Anyone know a good phone application to count carbs and food?” (1- Jack)*

*“You have to inform the DVLA if you are taking a medication that contains insulin” (2- Evie)*

*“Have a look at this guide about driving and diabetes: [external link]” (2- Oscar)*

*“I’m looking for travel insurance for people with diabetes, any advice” (2- Ella)*

Members mainly showed two main motivations to seek diabetes-related information. They either had a recent episode of poor health or had a gap in their knowledge that needed to be fulfilled. In the first instance, phrases such as *I’m not feeling well* and *my blood sugar level is too low* were expressed before or after seeking the information. In the case of having a gap in the knowledge, other phrases such as *I do not know what to do* and *am I right?* were used to let other members know about their needs. In return, members shared their knowledge and experience that they learned over time with other peers in the OSGs. Although the motivation

to share information on OSGs was not clear from the data, the literature suggested that members shared health information on online communities to show “reciprocity, altruism, and empathy” (Zhang, Liu, Deng, & Chen, 2017, p. 797).

Threads and posts in this sub-theme showed how members sought and exchanged information regarding different issues related to diabetes. Members mainly asked and answered questions, as well as exchanged experiences regarding food, blood sugar levels, test results and medications.

#### **4.3.2.4.2 Information related to communicating with HCPs**

This sub-theme revealed concerns and techniques members exchanged to communicate effectively with their HCPs. In this sub-theme, members exchanged information about different issues such as how to maximise the benefits of attending HCP appointments, how to deal with uncooperative HCPs and patients’ rights, as shown in the examples below:

*“What should I have said to my HCP so he listens to me and reduces the medication that makes me sick? He does not listen to patients; all he cares about is ticking boxes” (2- Millie)*

*“[after explaining the medical history] Can anyone please explain what might happen [with the HCP] when I go to the hospital in few days?” (1- Charles)*

*“You have been mistreated! I advise you to change your HCP” (2- Freya)*

*“To get the most of your meeting with your HCP, try to write down all questions you have in a paper in advance and order them based on their importance” (1- Ava)*

*“Is it important to tell my dentist that I have diabetes?” (2- Jacob)*

*“If your pharmacist does not give you what on your ‘repeat’ prescription, it might be wise to change the pharmacist or speak to your GP about it” (2- Oscar)*

*“The NICE gave a room for HCPs to prescribe when they think it’s needed ... this is not acceptable ... when such decisions are challenged, good consequences happen” (2- Isla)*

A number of reasons led members to seek information about how to deal with their HCPs.

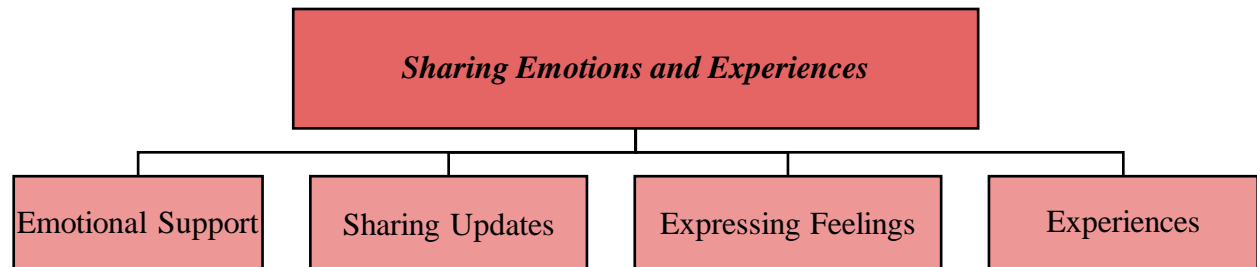
First, when seeking information, many members expressed that they disagreed with their

HCPs about a treatment plan and, as a result, they were uncertain about which health action to take. The disagreement led to uncertainty, which made members seek informational support from peers either to confirm their position (treatment choice) or suggest other alternatives. Second, members sought information to optimise their visits to their HCPs. They reported that they had a very limited amount of time with their HCPs and, therefore, wanted to use that time effectively to discuss or take what they needed. Third, a number of members were uncertain about how their HCPs would react when informed about a health action that patients made without their consent. For example, some members sought information on how to tell their HCPs that they were on a low-carbohydrate programme. They knew that their HCPs were against the health action they took, therefore, they needed the support of their peers to help them inform their HCPs and help keeping them on their side. Lastly, members sought information to help them understand their rights and the health care system. For example, a number of members thought that they were eligible for prescriptions that they could not get. They therefore used the OSGs to seek information about their rights and how to take a legal action to receive their rights.

In summary, this sub-theme illustrates how OSGs were used to seek, obtain and exchange information that helped members to know how to effectively communicate with their HCPs, how to cope with different difficulties that might arise with HCPs and their legal rights in relation to HCPs. As this section has shown, many members believed that their HCPs were a main source of support for them. They were therefore keen to get the most out of this source. They were looking for ways to maximise the help they get from their HCPs and approaches to resolve any issues that might limit them from benefiting from their HCPs.

#### 4.3.2.5 Sharing Emotions and Experiences

This theme encompasses threads and posts that contained sharing emotions, experiences and general life updates (Figure 4.7).



**Figure 4.7 Subthemes of the theme: Sharing Emotions and Experiences**

##### 4.3.2.5.1 Emotional Support

This sub-theme identified emotional support exchanged between members in the OSGs. Members showed sympathy and support when other members felt down or had difficult situations. They also encouraged others when they had positive and negative results, as explained in the examples below:

*“You are doing great! WOW it is a wonderful improvement” (1- Sarah)*

*“Great test results! Keep doing whatever you are doing” (3- Ellie)*

Members showed love and encouragement to those who expressed that they were perceived negatively by others because of their diabetes or they were blamed by their HCPs because they did not make good progress, as explained in the examples below:

*“It is NOT your fault to have diabetes. There is NO shame in that. It’s a disease ... much love to you” (1- Katelyn)*

*“You have tried hard, forget about the negative vibes [from your HCP]. Any person who thinks it is an easy process, they have no idea! Best of luck” (1- Madeline)*

Whilst informational support is key in OSGs, emotional support has a higher influence on patients’ health improvement (Yan et al., 2014). On different occasions, members sent

messages to others emphasising that they were not alone and they were available whenever they needed help. Emotional support was highly valuable in serious situations (as seen in Section 4.3.2.1.2) or when a member was feeling down. Emotional support also encouraged members to continue performing activities that helped them to manage and control their diabetes. This type of support was found to be one of the main goals for people who seek to manage diabetes when interacting with other members in online platforms (Newman et al., 2011). The support exchanged in the OSGs gave other members a signal that they were valued and not alone. It made many of them feel better when they knew that other members faced the same challenges and highs and lows. Newman, Lauterbach, Munson, Resnick and Morris (2011) noted that people with diabetes preferred seeking emotional support from OSGs over other online platforms, such as Facebook, because members on OSGs had the same types of challenges, provided encouraging messages and responded within a short time. Further dissuasion about emotional support is presented in Section 4.4.10.

#### ***4.3.2.5.2 Sharing Updates***

Updates about recent blood test results, HCP visits and other health-related news shared between members are identified in this sub-theme. Members shared the updates with others to keep them informed about their health status or to seek informational and emotional support. Members also shared their positive progress and thanked other members who helped them to reach the improvement, as illustrated in the examples below:

*“After changing my diet and not eating a few things, I managed to reduce my HbA1c to 50” (3-Elizabeth)*

*“Had my review today. Happy! HbA1c down from 70s to 30s. Weight also 15 kg down! My blood pressure, eyes and feet are also good! ... thanks all for helping me to achieve my goals!” (2-Muhammad)*

*“I was diagnosed 3 months ago. Just had my review. HbA1c decreased 10 points to 57. Very happy with the results ... thank you all for the information, advice and encouragement” (1-Kylie)*

The data showed that members shared more news about positive improvements than about negative ones. This might be because they wanted to thank them, directly or indirectly, for providing the support they needed to help them reach the positive results. However, when having negative news, they shared them in another form (e.g. direct or indirect questions). These questions focused on the aspects that were negative and they asked how to overcome them, as explained in the following examples:

*“I’m stressed and my sugar levels went up this month. What do you do guys to keep your levels down?” (I- Jonathan)*

*“My HbA1c is double what it should be ... I always feel bad in the morning and have a headache ... I’m doing what I have been told that I should do ... I’m losing weight too ... I’m rambling sorry” (I- Jacqueline)*

Members shared their negative updates to obtain informational and emotional support that would help them overcome the health challenge they were facing (mostly to go back to normal blood sugar levels).

#### **4.3.2.5.3 Expressing Feelings**

This sub-theme revealed members’ emotions towards having T2D. Members used OSGs to share their concerns, fear, shame disappointments and other emotions, as explained in the examples below:

*“I’m scared that I will not be able to get pregnant in the future [because of diabetes]” (I- Jacqueline)*

*“My review in a couple of weeks, it’s going to be bad I know!” (I- Laura)*

*“I rarely tell people I have diabetes; I feel ashamed ... I was overweight but now I’m in the healthy range ... I feel ashamed of my diabetes that it was my fault because I was very fat ... I am terrified from the future ... do you feel the same?” (I- Faith)*

*“I stopped eating in public places a couple of years ago because I felt ashamed. I found it hard to tell my friends about my diagnosis” (I- Katelyn)*

When they were newly diagnosed, some members had concerns about the uncertainty of a future living with diabetes. The lack of information about the nature of the condition might have caused that fear. Coping with the uncertainty of the condition is one of the elements in the HCE model (Johnson, 2011). When members expressed their concerns, fear, disappointment and other feelings, other members provided emotional support (Section 4.3.2.5.1) and information support (Section 4.3.2.4). They also shared similar experiences and stories (Section 4.3.2.5.4) to help them stay calm and feel that they were not alone in experiencing such feelings.

#### ***4.3.2.5.4 Sharing Experiences***

Members exchanged their experience in managing and controlling the condition which is identified in this sub-theme. On different occasions, when members sought information or expressed their feelings towards an issue, other members replied with their experience, as explained in the examples below:

*“I have found that not having breakfast and lunch is helpful to lose weight, as well as walking for about 20 miles every day” (I- Jose)*

*“I know how you feel, I felt the same ... usually, I have some food or glucose jellybeans on me to eat when I feel my blood sugar levels is low. It helps to stop the feeling” (I- Addison)*

Members shared their experiences with others to provide informational or emotional support directly or indirectly. Members valued others' experiences and some of them valued others' opinions over other sources of information (such as their HCPs) because they had first-hand experience with the condition themselves, and not only studied it:

*“It is useless to ask my HCP, I would rather ask you here. People here speak from experience not out of the book” (I- Alexandra)*

*“HCP recommendations are not always as helpful as the ones you get here from people with experience with diabetes” (I- Addison)*

Experiences shared in health OSGs helped peers to find information, feel supported, preserve relationships with other people, navigate through the health care system differently and change health behaviours (Ziebland & Wyke, 2012). Some health care systems, such as the NHS, value sharing experiences among patients on OSGs and believe that helps to improve the health quality and make a cultural change (NHS, 2012). However, as shown earlier, HCPs had different perspectives regarding using the OSGs and sharing experiences.



## **4.4 Discussion of Posts Study's Findings**

### ***4.4.1 Introduction***

This section discusses the results of the study in relation to the literature. It is structured based on the topic discussed. These findings are discussed in more detail when both studies' findings (i.e. the posts and interview studies) are discussed together in Chapter 6.

### ***4.4.2 Conflicting information***

The HCE model highlights the role of cultural, social and environmental factors in influencing different empowerment elements. The study showed that members faced various issues related to the management of their condition that created a tension between patients and their care providers. These issues were a result of policies and practices implemented by the care system. For example, members in the OSGs repeatedly expressed the view that the NHS limited their ability to effectively control and manage the condition by not allowing them to self-monitor blood glucose (SMBG). Although the NHS does not generally recommend SMBG for non-insulin dependent T2D (NICE, 2017), SMBG could effectively help people with T2D to adjust their diet, exercise regime and daily habits to reach glucose goals, even for those who are insulin dependent (Kennedy, 2001; Welschen et al., 2005). Members in similar situations received conflicting advice from their HCPs either in favour or against SMBG.

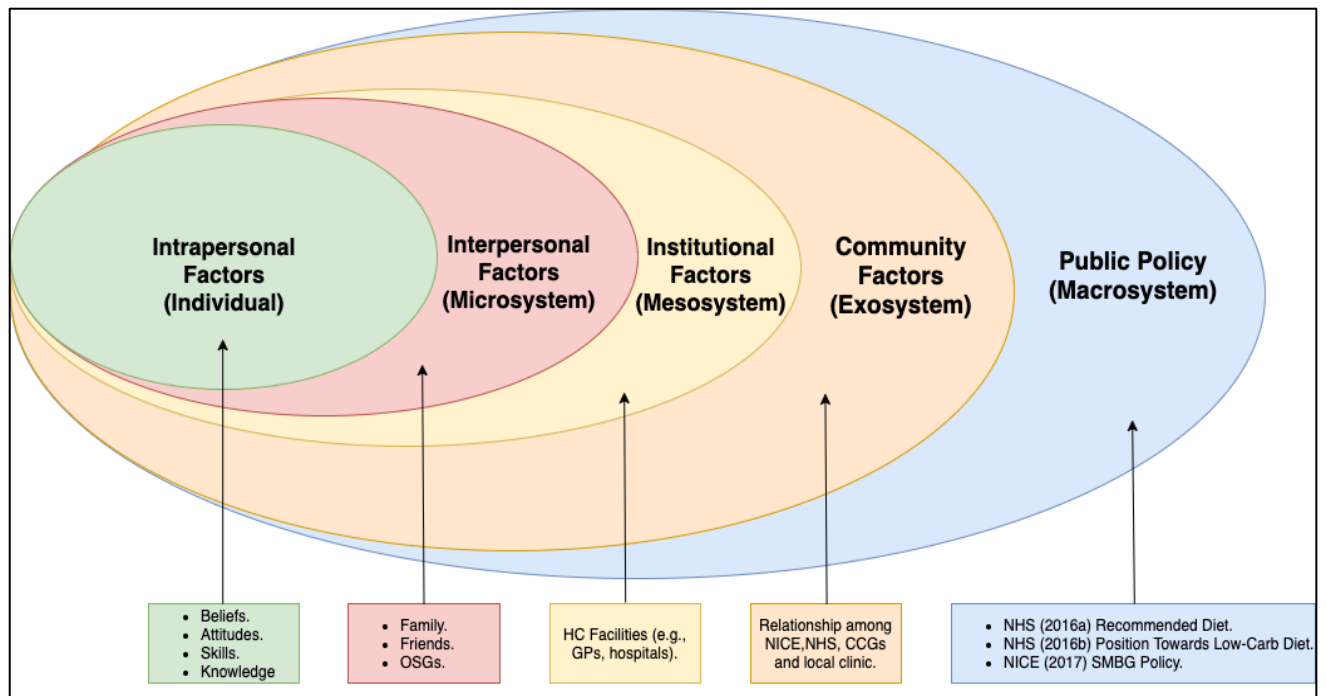
Similarly, in diet recommendations, weight management should be the main nutritional approach in managing glucose levels for people with T2D who are overweight (Dyson et al., 2011). This can be reached via a number of methods, including reduction of calorie intake (Dunn et al., 2018). A number of people with T2D, as shown in the findings, chose to manage their weight and blood glucose by following a low-carbohydrate diet that has been

reported by a number of studies to be safe and effective in the short term (Dyson et al., 2011; Dyson, 2015; Hussain et al., 2012; Nielsen & Joensson, 2008; Saslow, Summers, Aikens, & Unwin, 2018; Snorgaard, Poulsen, Andersen, & Astrup, 2017; Yancy Jr, Foy, Chalecki, Vernon, & Westman, 2005). However, the diet was found to be less effective, but still safe, in the long term (Dyson, 2015; Naude et al., 2014; Snorgaard et al., 2017).

The NHS has repeatedly and clearly explained that it aims to empower patients with chronic conditions to make their decisions by themselves and manage their conditions independently. In its *Five Year Forward View* (NHS England, 2014), for example, the NHS stated that its aim is “to help patients make informed choices” (p. 32) because “England is too diverse for a ‘one size fits all’ care model to apply everywhere” (p. 4). In relation to diabetes care in particular, NHS England (2014a) aims to “empower patients with information to support their choices about their own health and care” (p. 7). The vision set out in the *Five Year Forward View* is now in its final year (i.e. 2020/21), and the findings of the present research suggest that the choices of people with T2D to manage their own health have not been considered. The information provided to them was selective and did not include many diabetes management and control approaches that were found useful by many people. For example, information about approaches to manage and control T2D through a low-carbohydrate diet was not provided to people with T2D by the formal health care channels. In addition, they were not given the freedom to make decisions that they felt were the best for them. This contradicts the NHS’ stated intention to support the choices of people with diabetes by providing the necessary information to enable them to do so. In the findings, members reported negative consequences for their relationship with HCPs when making their own decisions about controlling and managing their condition, especially in relation to diet and SMBG. They repeatedly highlighted the importance of accepting patients’ choices to manage the condition. HCPs’ disagreement with patients’ treatment decisions resulted in a gap

opening up between HCPs and patients. It also led to patients using different sources, such as the OSGs, to seek information that had not been provided. Therefore, the findings strongly suggest that information about different approaches and techniques to manage and control T2D should be available. The opinions of HCPs and the health care system should not have the effect of preventing information about other approaches and techniques being accessible. HCPs can explain their opinions about the approach they believe most appropriate for a patient. However, they should also respect the patient's choice and their freedom to make it. Therefore, the findings recommend that information about all types of safe approaches used to manage and control T2D should be available and people's preferences should be respected and considered.

The Social Ecological Model (Bronfenbrenner, 1979) can be used to illustrate the controversial topics of SMBG and low-carbohydrate diet for people with T2D which emerged in the findings (Figure 4.7). The model explains how an individual is influenced through four levels/layers.



**Figure 4.8 Application of the Social Ecological Theory to controversial topics found in the present study. Data Source: Adapted from Bronfenbrenner (1979)**

The model's higher level/layer is the *macrosystem*, which refers to general social influences such as government policies and economic situations (Adamsons et al., 2007). In this case, the NICE (2017) SMBG policy, the NHS (2016b) position on low-carbohydrate diets and the NHS (2016a) recommended diet for people with T2D can be seen as the highest level that influences all other levels and the individual.

The next level (*exosystem*) represents community factors, including the relationships between organisations and institutes; these factors do not involve the active participation of the individual (McLeroy et al., 1988). The relationship among NICE, Clinical Commissioning Groups (CCG) and local clinics can be represented in this level. In this level, different interpretations of the policies implemented in the previous level occur. The interpretation and application of the policies varied, and members reported that policies were flexibly and strictly applied. The exosystem level/layer can also be seen as a power structure where the

agenda is placed and prioritised and resources are allocated (McLeroy et al., 1988), which might explain the inconsistency in the application of some policies such as SMBG. A 2016 UK survey of people with diabetes showed the inconsistency among NHS facilities of prescribing test strips, with some not doing so to save money (Diabetes UK, 2017), resulting in what has been described as a “postcode lottery” (Diabetes UK, 2013, p. 1). The power structure that takes place at the exosystem level might explain the difficulties many members reported of their dealings with their HCPs.

The next level (*mesosystem*) is related to institutional factors, such as GPs and their formal and informal operation regulations. For instance, in the findings, a number of members with a similar diabetes status reported different treatment recommendations from their HCPs. Some of them were prescribed and advised to SMBG and others were not. Likewise, in the low-carbohydrate diet, some HCPs accepted a patient’s option to follow the diet. Others, however, were stricter and intolerant. This illustrates how institutional factors and operation rules (including their understanding and application of the policies) can directly influence individual management of diabetes.

The next level is the *microsystem*, which is the immediate environment around the person (Adamsons et al., 2007). It is represented in this study by family members, friends and OSG members. They play a direct and influential role in supporting an individual’s diabetes treatment. In the findings, many members reported that they acquired information about new treatment options from their peers in the OSGs and friends. Others, as indicated in Section 4.3.2.2.3, highlighted the importance of their family members in supporting and agreeing with their treatment options. This suggests that this layer/level plays a very important role as

a source of advice and support that helps the individual to interpret, challenge and learn about the higher levels.

The last level represents individual factors such as knowledge, beliefs, health literacy and ability to use technology to fulfil information needs. These factors can influence the way in which people with T2D control and manage diabetes. For instance, curiosity to discover more treatment options led some people to join the OSGs. Others believed that they should favour experience-based medicine over evidence-based medicine, which led to them following the low-carbohydrate diet. The model can be employed for greater understanding of different factors/layers that influence people with T2D and their decisions about managing the condition.

#### ***4.4.3 Information types and health behaviour change***

Members of OSGs exchanged information mainly about diet, medications, complications and physical activities. This is consistent with the findings of Kuske et al. (2017), who looked at 26 information-seeking studies of people with diabetes (see Section 2.3.2). Kuske et al. (2017) and Longo et al. (2010) reported that, even though the Internet was highly used by people with diabetes to seek information about their condition, HCPs remained their primary source of information. However, in this study, many members reported that they used OSGs, and the Internet in general, as their primary source of information to learn about diabetes. The use of the Internet as a source of information for people with diabetes has been shown in a number of studies to be preferred by younger people and those with a higher education level (Giménez-Pérez et al., 2016; Jamal et al., 2015; Kalantzi et al., 2015; Lui et al., 2015;

Robertson et al., 2005). However, this finding could not be corroborated by the data collected for this research, since members' ages and education levels were unknown.

Members reported that the information exchanged in the OSGs had a positive impact on their health. It mainly helped them to manage and control their blood sugar levels, to lose weight and to adopt and maintain other healthy behaviours. The anonymity and non-judgmental nature of OSGs allow members to exchange social and informational support that helped them to achieve health goals, as reported by Hwang et al. (2010). These authors reported that "encouragement and motivation, information and shared experiences" (p. 11) helped OSG members to achieve their weight-loss goals. OSGs might also offer a unique source of support that encourages members to change their health behaviours by seeing how successfully other members are able to make such changes. An individual's success in achieving his or her own health goals is associated with the success of peer supporters in achieving their goals in a number of health conditions, such as obesity (Gorin et al., 2005). In T2D care, peer support plays a key role in helping people achieve their goals (Van Dam et al., 2005). Peer support has been found to be more effective than HCP management in diabetes care (M. Heisler et al., 2010). When supporting their peers in the OSGs, members reassured others that they had the ability to control and manage the condition, and this reassurance was linked to positive health behaviour change and adoption of new healthy habits (Embuldeniya et al., 2013). The likelihood of making a health decision and adopting a healthy habit can be attributed to a variety of reasons, such as the perceived seriousness of the condition and its complications (Becker & Maiman, 1975). However, when seeking health information in the OSGs, many members reported that their negative current health status, HbA1c or their fear of the severity of the condition caused them to seek the information. The HBM represents this factor as "*individual perceptions*" of the severity of the condition that

might influence the likelihood of taking a recommended health action. Peers in the OSGs served as “*cues to action*” with the shared recommendations and experiences provided, which influenced the action taken. However, the HBM does not consider environmental factors, such as HCPs and the HC system, which might influence the promotion or prevention of taking the action. The maintenance of the action led to changes in health behaviour that many members reported as resulting from using the OSGs; this, in turn, led to better control and management of the condition.

As the Transtheoretical Model (TTM) explains (see Section 2.3.4.1), people move through a set of stages when changing their behaviours. The findings revealed that members used the OSGs at different stages to obtain information or emotional support that would assist them in taking and maintaining their actions/behaviours. For instance, in the *preparation* stage, members asked their peers about the number of carbohydrates the low-carb diet involves (see Section 4.3.2.3.2). They were convinced that the diet would help them and took the first steps to start it.

As presented in Section 4.3.2.1.3, members reported their progress after a few months of making a health action based on the information they obtained from the OSGs, which can classify them as being in the *action* stage. For the most part, they posted in the OSGs to share their positive progress (and, consequently, to receive encouragement), to express appreciation of peers who had helped them, or to seek more information about the action taken. However, a relapse to old unhealthy behaviours usually occurs during the *action* or *maintenance* stage (Prochaska et al., 2008). Members used the OSGs as a source of emotional support during the *maintenance* stage. As shown in Section 4.3.2.1.2, *I-Tracy* used the OSGs to maintain the



healthy behaviour of not eating sugar and avoid the relapses that she had experienced in the past. She kept posting over the year to help her maintain the adopted behaviour. *Tracy* maintained the behaviour for over a year, while also sharing her experience and offering advice to peers who were addicted to sugar. The findings suggest that members used the OSGs mainly to obtain information support in the *preparation* stage, information and emotional support in the *action* stage, and emotional support in the *maintenance* stage. However, this finding would merit further examination.

#### ***4.4.4 Doctor–patient relationships***

Various members described their relationship with their HCPs in a tense tone. Members reported that they were treated without considering individual differences between them and other patients (e.g. different reactions to food, different medications), which made them struggle. This is consistent with St Jean (2017) who reported that the “cookie-cutter, one-size-fits-all” treatment approach acts as a barrier that prevented people with T2D from seeking diabetes-related information, causing some of them to seek diabetes-related information on the Internet. OSGs allowed members to compare their experiences with health care services with the experiences of other members. Members used OSGs in this way to know if they were well treated and informed or not. After reading about their peers’ experiences, several members understood that they had not been offered the right information and treatment.

Members also emphasised following experience-based medicine over evidence-based medicine. For example, they repeatedly confirmed that following the LC diet resulted in positive control and management of the condition. Many reported that the only reason their HCPs did not recommend the diet to them was the lack of medical evidence supporting the

diet and its long-term consequences. Members frequently stated that they were not willing to wait many years for medical evidence when their bodies were reacting positively to the diet. This indicates that members preferred to follow their own experience over evidence-based medicine. Members who had not previously tried the diet were convinced by seeing other members' positive experiences, attributing a higher value to the knowledge and experience of other members than to the knowledge of their HCPs. Similarly, Kazmer et al. (2014) found that members in amyotrophic lateral sclerosis (ALS, also known as Motor Neurone Disease [MND]) OSGs valued the knowledge of other patients over their HCPs' knowledge. They considered their peers to be "expert patients" who have the ability and knowledge to help others find the information they need. When a member provides information, other peers validate it from their own experience. This suggests that the collective community effort in the OSGs to provide and validate experiential information make them a preferred source of information for many members. When the experiential information was inconsistent with the information provided by HCPs, members valued the former more highly because it had come from an experienced individual with the condition.

Charles, Gafni and Whelan's (1999) model suggests that HCPs are the primary source of information for patients, particularly of information about the latest scientific-based treatment options. However, patients in the model usually come to HCPs with their own experiences, treatment-option information, opinions, values and feelings, which they use to interpret the information provided by their HCPs. Therefore, patients' factors need to be considered when providing information to patients. Effective interaction between HCPs and patients is emphasised when making treatment decisions. Patients' preferences in treatment options should also be considered and negotiated. Charles et al.'s (1999) model explained that if patients and HCPs cannot agree on treatment decisions, HCPs can decide whether or not to

adopt or negotiate patients' preferences. In the findings, members revealed different reactions by HCPs to their preferences. Some of the HCPs who did not agree with the LC and LCHF diets advised their patients to start with LC diet, not with the HF diet. They also advised them not to go too low at the beginning and to take it step by step. This shows how some HCPs negotiated with their patients and adopted their preferences. Members regarded their HCPs favourably if the HCPs had adopted the members' preferences. Other HCPs, however, totally ignored members' preferences, which resulted in conflict or disengagement between them and their patients. According to Charles et al.'s model, patients are advised to find another HCP who would support their preferences if their current HCP is unable to agree with those preferences. In chronic conditions, such as T2D, it is important to consider patients' values, preferences and social factors, because the treatment occurs in patients' spaces over their lifetimes (Montori et al., 2006). HCPs follow guidelines and policies from the HC system that aim to standardise care, but this tends to ignore patients' preferences and social factors (Vijan et al., 2005) and individual needs. Consideration of patients' informed preferences represents the ideal practice of evidence-based medicine (Montori et al., 2013). However, tension between patients and HCPs in diabetes care was highlighted by Cooper, Booth and Gill (2003) who explained that, because of the different knowledge levels and backgrounds of patients with chronic conditions and the patients' HCPs, potential conflicts might occur. Cooper et al. (2003) recommended, therefore, including social and medical sciences in HCPs' education to increase the awareness of such issue.

#### ***4.4.5 Patient involvement***

The findings suggest that patient involvement in the control and management of diabetes is highly important to many OSG members. Members emphasised the role of patients as experts in dealing with the condition. Expert patients are those "who have the confidence, skills,

information and knowledge to play a central role in the management of life with chronic diseases and to minimise the impact of disease on their lives” (Department of Health, 2001, p. 9). Members highlighted that they have to deal with the condition on a daily basis. Therefore, they need to be active patients who have expertise in dealing with the condition. They refuse to be passive patients who, according to members’ definition, take the required medications and remain with the unhealthy behaviours. Active patients can easily be seen in the OSGs since they are actively looking for information that help them control and manage their condition. The findings suggest that this type of patient tends to challenge HCPs and their decisions. For example, if their HCP advised them not to self-test blood glucose every day, they would object and self-test anyway. Passive patients, on the other hand, are not as visible in the OSGs. This may be because they prefer to be in a paternalism relationship with their care providers (as explained in Section 2.7.4.2) and follow their instructions without looking for other sources of information. This, however, requires further investigation (see Section 7.6 and 7.7).

#### ***4.4.6 Expert patients***

The term *expert patient* has been widely discussed in the literature (Fox et al., 2005; Wilson et al., 2007). The concept of the expert patient has been introduced and adopted by the UK Department of Health (2001) with the intention of providing patients who have chronic conditions with the required confidence and skills to enhance the quality of their lives and to build a partnership with HCPs (Shaw & Baker, 2004). A number of members frequently explained that people with T2D have to be expert in the condition and to use all mediums, such as OSGs, to obtain the required knowledge and skills to control and manage the condition. The findings suggest that the OSGs served to facilitate members to become experts, which is consistent with Van Uden-Kraan et al.'s (2008) study of breast cancer,

arthritis, and fibromyalgia OSGs, which reported that OSGs offer the necessary assistance for patients to enable patients to acquire the characteristics of the *expert patient*.

#### **4.4.7 Information credibility**

A number of members who mentioned to their HCPs that they had obtained information from OSGs reported negative reactions from their HCPs about the credibility of that information. This finding is consistent with Rupert et al. (2014), who found that the majority of HCPs reacted negatively to the content of OSGs, thereby “making participants feel disempowered” (p. 320). These reactions might have frustrated members, although this needs further investigation in the next stage of this study. The findings indicate that a large number of OSG members favoured the information provided by their peers over the information provided by their HCPs because their peers had first-hand experiences. Others questioned HCPs’ knowledge because the HCPs had been trained years ago. The next study presents more findings regarding information trust in Sections 5.3.2.1.4 and 5.4.3.

#### **4.4.8 Self-management education**

The findings suggest that information provided to patients after the diagnosis was not as helpful as they had expected. A number of people described the information provided in the courses as generic and not practical. It is highly recommended that diabetes self-management education be personalised and that it consider patients’ backgrounds, values, traditions, religion, and other factors (American Diabetes Association, 2018; Beck et al., 2018; Rankin et al., 2012). However, some members reported these factors as missing from the educational courses they attended. The findings suggest that freedom of information about different approaches to managing and controlling the condition should be discussed between HCPs and newly diagnosed patients, which would make patients aware of the available approaches.

HCPs are responsible for recommending the approach that they think is most appropriate for a patient. However, many members expressed their desire to be informed about all available approaches so that they can then navigate through them. Thus, the findings indicate that concealing information about some approaches for the management and control of the condition (such as following a low-carbohydrate diet) does not benefit those patients who might find these approaches useful. Further findings and discussion about information and education provided to people with T2D using OSGs are presented in Sections 5.4.2 and 6.2.

#### ***4.4.9 Family support***

Members expressed the importance of family support for their self-management of diabetes. Some members reported that they had been supported by their families, expressing their appreciation of this support; however, others voiced their concerns about disagreements with family members on issues related to the management of their diabetes. This indicates the importance members attached to family involvement with and support for their diabetes management. The HCE model emphasises social and environmental factors as having the strongest influence on personal resources, intrapersonal factors and empowerment elements. The finding that family influence plays an important role in patients' self-management of T2D is consistent with previous studies (Handron & Leggett-Frazier, 1994; Minet et al., 2011; Rosland et al., 2010). Although the data in the findings does not show the extent to which family members influenced members' empowerment, it does reveal that the person's family was often an important source of support that enabled members to control and manage their diabetes. When members disagreed with their families about issues related to diabetes management, they asked their peers in the OSGs about how to convince their families to be on their side. This shows that family members played significant roles in the patient's management of the condition; therefore, patients wanted their families to be on their side.

Family members could play various roles in patients' managing their condition, such as information gatherers or interpreters, negotiators, coaches, advisors and caretakers (Charles et al., 1997). People with diabetes were found to rely on family members and friends to support and approve information found on the Internet. Family involvement is especially important in the management of chronic conditions because of the potential consequences, stress and uncertainty experienced by patients over their lifetimes.

#### ***4.4.10 Emotional support***

Emotional support was widely exchanged between members in the diabetes OSGs, and this has also been found in OSGs for other conditions such as prostate cancer (Huber et al., 2017) and breast cancer (Hargreaves et al., 2018). Members expressed their thoughts and emotions to their peers on the OSGs because they felt that other members had gone through the same experiences and, hence, had a better understanding of the feelings associated with these experiences. Hargreaves, Bath, Duffin and Ellis (2018) also highlighted that OSGs provide a unique source of emotional support and empathy that could not be provided by family members, friends and HCPs. Members exchanged phrases such as "*I know how you feel*", "*I feel you*" and "*I went through that too*" to show empathy and support to others who were having a hard time. The exchange of emotions and empathy helped members to overcome difficult situations and encouraged them to achieve their diabetes goals. Bond, Burr, Wolf and Feldt (2010) reported significant psychosocial and self-efficacy improvements for elderly adults who participated in diabetes OSGs. The findings suggest that OSGs are an important and unique source of emotional support for people with T2D.

## 4.5 Conclusion

This chapter has sought to better understand the influence of information and emotions exchanged in three UK OSGs among people with T2D on the management of their condition. It has presented an examination of messages exchanged across the OSGs to understand the information needs, behaviours and utilisations of people with T2D; the influence of OSG use on members' empowerment; and the role of the factors identified by the HCE model on members' empowerment. The analysis of 814 messages from 250 unique members identified five main themes.

The findings suggest that members used the OSGs to obtain informational and emotional support that helped them to learn about their condition, to overcome barriers and, as a result, to control and manage the condition effectively. Members mainly needed and exchanged information regarding food, SMBG, medication, interpretation of tests, and techniques to help set and achieve goals. The OSGs enabled members to discover information and to learn about treatment options that were not provided by HCPs. Members also learned about their legal rights and how to cope with HCPs. Moreover, the OSGs were used as a way to compare the health care service and information provided by HCPs to members. This suggests that OSGs can facilitate shared decision-making that helps members to be aware of treatment options, benefits and risks.

In relation to empowerment, patient engagement and involvement in their own health care was not fully supported by HCPs and the health care system. First, selective or very limited information about managing and controlling their condition was provided to patients, which meant that the patients were not fully informed. Second, when patients obtained information from other sources to help them manage and control their condition and to adopt other



approaches, many HCPs did not accept the options discovered by the patients themselves. This led to a gap / tension between some members and their HCPs, which led them to rely on the OSGs and other sources to manage and control their condition. It also made them hide their treatment plans from their care providers. As a result, the findings indicate that providing patients with selective information and not accepting the patients' choices might lead to the patients becoming disempowered or to the creation of friction and cracks between patients and care providers.

The findings show that emotional and family support were very important for helping OSG members to overcome hard times and achieve their goals. Patients used the OSGs as a tool to seek emotional support and to learn how to have their family members on their side.

The aim of the first stage of this exploratory study was achieved. The three OSGs were investigated to explore indications of empowerment/disempowerment. In particular, it examined the need for information and the information-seeking behaviours of people with T2D, as well as the influence of various contextual and intrapersonal factors and personal resources on patient empowerment and the health behaviours of people with T2D. This chapter especially addressed the following research questions:

- *What are the information needs and behaviours of people with Type 2 diabetes using OSGs?*
- *How do the various contextual and intrapersonal factors and personal resources influence patient empowerment for people with Type 2 diabetes?*

This stage richly informed the second stage. It helped the researcher understand members' needs and challenges and how they used the OSGs to enhance their empowerment status.

Although this stage was informative, it did not provide answers to some of the research questions. In particular, it did not provide insights about how OSG users utilise the information they receive from the OSGs, how OSGs change members' health behaviours, and how members start their information-seeking journey to become informed. These questions were investigated in more detail in the next stage and are addressed in Chapters Five and Six, which outline the Interview Study and the subsequent triangulation of results from both studies.

## **CHAPTER 5 : INTERVIEW STUDY**

### **5.1 Introduction**

This chapter presents a thematic analysis and discussion of interviews conducted with people affected by T2D regarding their use of OSGs to control and manage their condition. While the previous chapter investigated how the OSGs were being used by their members through the collection and analysis of their posts, this chapter used in-depth interviews to examine in more detail how members used the OSGs, their journey to find information and how that influenced their empowerment through with OSGs members. Further details about the study design and the ethical issues considered in carrying out the study are discussed in Section 5.2. The chapter then presents the sample characteristics and the results of the thematic analysis (Section 5.3). Section 5.4 discusses the findings of the analysis in relation to the literature. Finally, Section 5.5 summarises the key elements of the interview study.

### **5.2 Methods**

#### ***5.2.1 Study design***

The design of the interview study was informed by the findings from the analysis of the OSGs posts reported in Chapter 4, which provided insights about how the use of OSGs helped members to fulfil their information needs and how various factors influence their empowerment (see Section 4.5). However, it was not clear from the analysis of the posts how members utilise the information they received from the OSGs, their journey to find information and how that would influence their health behaviour. The study in Chapter 4 provided useful insights about conflicting information/issues that members had with their HCPs and how the use of the OSGs helped them to acquire more information about these issues. However, it provided only limited information about members' information behaviour in seeking information in OSGs and navigating between different information sources and

how they utilise the information they receive from OSGs. This part of the study aims to fulfil this gap by investigating into more details how members seek and utilise information and how that influence their health behaviour and empowerment. In particular, it aims to provide answers to the following research questions:

- *What are the information seeking behaviours of people with Type 2 diabetes using OSGs?*
- *How do patients with Type 2 diabetes utilise the information they receive on OSGs and how does this influence their health behaviours?*

The purpose of the interviews was to understand how members started their information journey, how they navigated through different sources, how they validated/trusted one source over another and how they implemented the information they acquired into a health action/behaviour. Participants in this study were all members of OSGs; therefore, questions were focused on how the information received from OSGs was utilised as well as their informational activities in the OSGs.

As explained in Section 3.8, interviews were undertaken until data saturation was achieved, which was expected to occur after conducting 15 to 25 interviews (see 5.2.2).

### ***5.2.2 Sampling and recruitment***

As explained in Section 3.8, participants needed to be adults (over the age of 18) diagnosed with T2D and who have used (or are still using) OSGs (either posting or just reading) to manage their diabetes for at least six months. Participants also needed to speak English and have lived in the UK for at least six months.

A call for participation in the study was posted in three OSGs, after obtaining approval from OSG moderators and ethics approval from the University of Sheffield (see Section 5.2.6). Based on the structure of the individual OSGs and recommendations from moderators, the call was posted in the Type 2 Diabetes board in DCU, the General Message board in DUK and the Research board in DSOU. The call was also advertised on the Research page of DCU's main website and on their Twitter page. The recruitment threads were updated several times to invite more participants.

The recruitment call included a Google registration form that allowed interested members to register their information. Potential participants were asked to enter basic information in the form (name, gender, city, OSG/s used, preferred interview method, email address and date/time availability). They were then contacted by the researcher on a first come first served basis. The invitation email contained information about the study, the recruitment criteria, the informed consent explaining the nature of the study and their rights (more details in Section 5.2.6) as well as suggested times for the interview. The email used an informal language (e.g. used the word *chat* instead of *interview*) to create a friendly and relaxed environment/relationship between the researcher and interviewee that would help them to speak openly and freely (Drabble et al., 2016; Farooq, 2015). Participants were offered to be interviewed either face-to-face, by phone/Skype or by email. The researcher ensured that participants had read, understood and signed the informed consent before proceeding with the interview. They also were informed that interviews would be audio-recorded. For the face-to-face interviews, participants were offered to be interviewed in the Information School or at a convenient and comfortable public location (e.g. a public library).

The recruitment continued until data saturation was reached, which is when new themes stop emerging from the data (Bowen, 2008; Mason, 2010). Data saturation was achieved after

conducting the 13<sup>th</sup> interview. However, four more interviews were conducted to confirm that no additional themes were emerging from the data.

### ***5.2.3 Piloting***

As explained in Section 3.8.1, the interview schedule, guide, consent form and demographic questionnaire were discussed with the supervisors and went through different versions until they were agreed upon. They were then tested on a colleague to ensure the clarity of the language used and to allow the researcher to practice their interviewing techniques. A few changes were made after the test interview to improve the clarity of the questions. Since “qualitative data collection and analysis is often progressive”, the researcher learned from each interview to enhance the subsequent one (Van Teijlingen & Hundley, 2001, p. 3). The researcher therefore reviewed the interview guide and process after each interview and made a number of changes. For example, the order, structure and focus of some of the questions were refined to allow more description and explanation. This technique served as a progressive learning process and provided important information about the implementation of the interviews (D. W. Turner, 2010) and helped the researcher to improve the questions (Chenail, 2011; Krauss et al., 2009). Furthermore, the first data collection and analysis method (the OSG posts study) helped the researcher to familiarise himself with the context of the topic before carrying out the interviews. This provided the researcher with more insights about what to explore and how to refine the interview guide and structure.

### ***5.2.4 Data collection***

Interviews started with the researcher introducing himself to the participant and establishing an informal chat to break the ice and create a relaxed atmosphere. The researcher then thanked the participant for taking part in the study and briefly explained the purpose of the

study, participants' rights, data confidentiality and the expected length of the interview. The researcher confirmed that participants had read the informed consent, were aware that the interview would be recorded and still agreed to take part in the study. Participants were also informed that they could stop the interview at any time, take breaks or skip any of the questions. Three phone interviews were stopped for a few minutes for various reasons (e.g., for one of the participants to take care of a child). The researcher assured the participants that the interview time was flexible and they could stop and continue when they were ready again. This flexibility contributed to a more relaxed atmosphere. At the end of the interview, participants were asked if they had any more information to share. They were then thanked again for their time. The researcher also explained what would happen next to the data and research in general. Participants were asked if they were interested to receive a summary of the findings when the study was completed. Appendix 7 explains the interview procedure and questions.

Interviews were conducted over a five-month period (from May to October 2019). Most participants who had full-time jobs preferred to be interviewed in the evening. Face-to-face participants preferred to be interviewed in the Information School.

### ***5.2.5 Data analysis***

All face-to-face and phone interviews were audio-recorded. They were then transcribed into Microsoft WORD™ 2016. The transcription process started directly after the first interview, and was repeated after every interview, so that all the essential details of what took place in the interview were recorded while still fresh in the researcher's mind. This process provided crucial information about the nature of each interview and helped to enhance the next one. It also helped the researcher to familiarise himself with the data and identify the data saturation

point (Hennink et al., 2011). As further explained in Section 5.2.6, in order to maintain anonymity, participants were assigned random aliases and all identifying information (e.g. the name of their GP) was removed from the transcriptions. Email-interviews were imported into a Microsoft WORD™ 2016 document. Access to all transcripts was given to the researcher's supervisors to enhance the data collection and analysis process (Lincoln & Guba, 1986). The interviews were discussed in several supervision meetings that helped the researcher to improve the data collection. The researcher followed Braun and Clarke's (2006) six-step approach towards thematic analysis, which was described in more detail in Sections 3.9 and 4.1.3.1. The implementation of the approach in relation to the interview study is described below.

#### ***5.2.5.1 Familiarisation with the data***

As described in Sections 3.8 and 4.1.3.1, this step involves “transcribing data (if necessary), reading and re-reading the data, noting down initial ideas” (Braun & Clarke, 2006, p. 87). Prior to the interview data collection, the OSG analysis of the posts study was conducted in the first stage of this research. Therefore, some understanding about how OSGs were used was gained from that first stage. As explained above, the researcher transcribed the data himself as part of this step. The process of familiarisation with the data continued after the transcription. The interviews were listened to multiple times, the transcripts were read and re-read, the interviews were summarised and notes and ideas for coding were taken. This process continued across the data collection and analysis and helped the researcher to immerse himself in the data.



### 5.2.5.2 Generating initial codes

The transcribed data were then imported into NVivo 11 to generate initial codes. Similar to the analysis in the previous chapter, described in Section 4.1.3.2, the researcher used inductive open coding as well as the HCE model to generate initial codes. As Table 5.1 shows, a data segment might have been coded to single or multiple codes (Braun & Clarke, 2006).

**Table 5.1 Example of data coding**

Data extract	Coded for	Rationale
<i>“My best friend when he told me that his diabetes [not his cancer] was going to kill him that shocked me into taking action to find out more about it. I felt so ignorant at that time.”</i>	Causes to take action about diabetes.	User alarmed by friend’s words to taking action.
<i>“So what I did was first try to see in the forum how many people? How extensive this was? I wasn’t just going on one individual say so ... I was looking for numbers you know ... when I posted and inquired some things ... I sometimes get a conflicting answer whereas sometimes that answer didn’t make any sense ...”</i>	The journey to find information about diabetes.  Conflicting information.	Obtaining the information is complex and involves different stages.  User gives direct indication that there were conflicting answers.

The analysis revealed 52 initial codes, which were reviewed continuously to eliminate repetition and ensure meaningfulness.

### 5.2.5.3 Searching for themes

The codes resulted from the previous step were examined to form potential themes. Relationships between different codes were identified and organised using mind-maps, as illustrated in Section 4.1.3.3 (Figure 4.1). Five main potential themes emerged from the analysis in this stage:

1. *Diabetes-related issues.*
2. *Information-related issues.*
3. *Drivers for people using OSGs.*
4. *Negative issues in OSGs.*
5. *Being a patient.*

#### **5.2.5.4 Reviewing the themes**

In this step, the identified themes were reviewed to organise and present them in a meaningful way. This process included combining themes related to OSGs in one theme and reorganising the others. The outcome of this process was three main themes: *Information and knowledge, Being a Patient and OSGs.*

#### **5.2.5.5 Defining and naming the themes**

The essence of each theme and the boundaries between others were identified in this step.

Table 5.2 below presents the definition of each theme.

**Table 5.2 Main themes emerging from the thematic analysis**

<b>Theme</b>	<b>Description</b>
<b>1. <i>Information and knowledge</i></b>	This theme describes the informational and knowledge status of participants before, once and after being diagnosed with T2D. It shows how participants navigated through and evaluated different sources to fulfil their information needs.
<b>2. <i>Being a patient</i></b>	This theme concerns how participants behaved as T2D patients. This includes how they dealt with the condition, reasons that motivated them to take actions and their beliefs about their role in the management and control of the condition.
<b>3. <i>Characteristics of OSGs for people with T2D</i></b>	This theme describes the different activities that took place in OSGs, the advantages/disadvantages of performing such activities and how the content and culture of an OSG was preferred over others.

#### ***5.2.5.6 Producing the report***

The findings and discussion of the analysis of the interview study are presented in Section 5.3. The aim of the write-up of the findings and discussion was to present the findings as a coherent account supported by the data from the interviews (Braun & Clarke, 2006).

#### ***5.2.6 Ethical considerations***

The researcher followed the University of Sheffield's ethics policy involving human participants (The University of Sheffield, 2016a). The researcher was aware of participants' rights. He, therefore, approached and treated them "fairly, sensitively, with dignity, and within an ethic of respect and freedom from prejudice regardless of age, gender, sexuality, race, ethnicity, class, nationality, cultural identity, partnership status, faith, disability, political belief or any other significant difference" (The British Educational Research Association, 2011, p. 5). The researcher followed a number of steps to achieve this. The purpose of the study was explained to potential participants in the recruitment call, when they were first contacted by email to arrange the interview and at the beginning of the interview. Participants were informed about their rights and how their data would be stored and analysed. The privacy, anonymity and confidentiality of their data was assured. They also were informed of the expected length of the interview, their right not to answer any of the questions, stop the interview and continue at any other time or withdraw from the study altogether. Their informed consent was obtained before undertaking the interviews (a copy of the information sheet and consent form is included in Appendix 6) and it was confirmed orally before starting the interview. To ensure the confidentiality and anonymity of the data, all participants were assigned random aliases and all personal and identifying information (e.g. HCP or clinic name) were removed. The researcher followed the University's ethics guideline to ensure that the study was conducted with honesty, integrity, minimal possible

risk to the participants and himself and respect to others and their beliefs (The University of Sheffield, 2016a). The interview study was ethically approved by the University of Sheffield Research Ethics Committee in accordance with the University's Research Ethics Policy (a copy of the ethical approval letter is included in Appendix 5). Further details about the ethics application can be found in Appendix 4.

### ***5.2.7 Member checking***

As explained in Section 3.11, member checking was used in this study to assure its validity, credibility and transferability. A summary of the key findings was shared with all participants of the study (Appendix 8): this was worded in a non-scientific language for better engagement (Birt et al., 2016). The participants were kindly asked to determine whether they felt that the findings represented their views. Four (out of the seventeen) participants responded to the message with confirmation that the shared findings were accurate and representative of their experience, as the following responses explain:

*"Thanks for the findings.pdf. It appears to be accurate."*

*"Thank you for the email. It looks fine. Regards."*

*"An interesting read, looks accurate, thank you."*

*"Thanks for sharing the findings. Seems accurate."*

This, therefore, helped ensure the quality of the study. In addition, it provided a summary of the findings for the interviewees in return for their participating in the study.

## **5.3 Results**

### ***5.3.1 Response rate and demographic characteristics***

This section discusses the recruitment response rate, participants and interviews' characteristics and the results of the analysis.

Although 33 persons signed up in the participation form to take part in the study, two of them did not meet the recruitment criteria (i.e. they did not have T2D) and 14 did not respond to the interview invitation email. The final number of recruited participants was 17.

In the following, participant characteristics and their diabetes and OSGs attributes as well as the interview features are presented.

#### ***5.3.1.1 Interview characteristics***

As explained in Section 5.2.2, participants were given the choice to be interviewed either face-to-face, by phone/Skype or email. The majority of the interviews were conducted by phone (n=15), one was face-to-face and one was conducted by email. The sixteen interviews ranged from 33 minutes to 105 minutes with a mean of 59 minutes and a median of 56 minutes. The transcription word counts ranged from 1,698-15,572 words with a mean of 6,722 words and a median of 5,772 words. For the participant who preferred to be interviewed by email, a total of 14 emails were exchanged, which resulted in a word count of 2,970 words.

#### ***5.3.1.2 Participant characteristics***

The demographic features of the 17 participants are presented in Table 5.3. As the table shows, most of the participants were white females, aged between 55 and 64, who worked

full-time, had a postgraduate degree, lived in towns and suburbs and were married or living with their partner.

**Table 5.3 Demographic characteristics of participants**

<b>Variable</b>	<b>Category</b>	<b>N</b>
Gender	Female	11
	Male	6
Age group	25-34	2
	45-54	3
	55-64	7
	65-74	5
Ethnic group	White	15
	Asian / Asian British	1
	Prefer not to say	1
Employment	Retired	5
	Full-time	6
	Household duties	1
	Self-employed	4
	Unable to work	1
Education Level	Secondary education or equivalent	3
	Post-Secondary education	1
	Vocational qualification	3
	Undergraduate degree or equivalent	4
	Postgraduate degree or equivalent	6
Area of Living	City	3
	Towns and suburbs	9
	Village/rural areas	5
Marital Status	Single	1
	Married/Civil Partnered	14
	Divorced	1
	Prefer not to say	1

### *5.3.1.3 Diabetes and OSG activity characteristics of participants*

Participants were asked general closed-ended questions about their OSG activities and diabetes history. Table 5.4 shows the breakdown of the participants from these questions.

**Table 5.4 Diabetes and OSG activity characteristics of participants**

Variable	Category	n
Number of years living with type 2 diabetes	Less than 1 year	3
	1-5	11
	6-10	2
	16-20	1
Use/have used medication to control diabetes	Yes, currently using	6
	Have used in the past but not anymore	3
	No, have never used	8
Received initial guidance when you were first diagnosed*	No	3
	Yes, from a doctor	2
	Yes, from a nurse	9
	Yes, from a dietician	5
	Yes, from a diabetes educator	4
Use/have used any of the following OSGs*	DCU	15
	DUK	9
	DSOU	2
	Others	4
Time using OSG	Less than 1 year	4
	1-5 years	11
	6-10 years	2
Member of OSG	Yes	17
Frequency of accessing OSG (either to write or just to read)	Several times a day	6
	At least once a day	7
	At least once a week	3
	At least once a month	1
Frequency of posting/writing on OSG	Several times a day	3
	At least once a day	8
	At least once a week	3
	Every couple of months	1
	Less than once a year	1
	Whenever I need information/support	1

\* Note: a number of participants selected more than one category.



### 5.3.2 Interview results

Three main themes emerged from the analysis of the seventeen interviews. Figure 5.1 shows the main themes and subthemes.

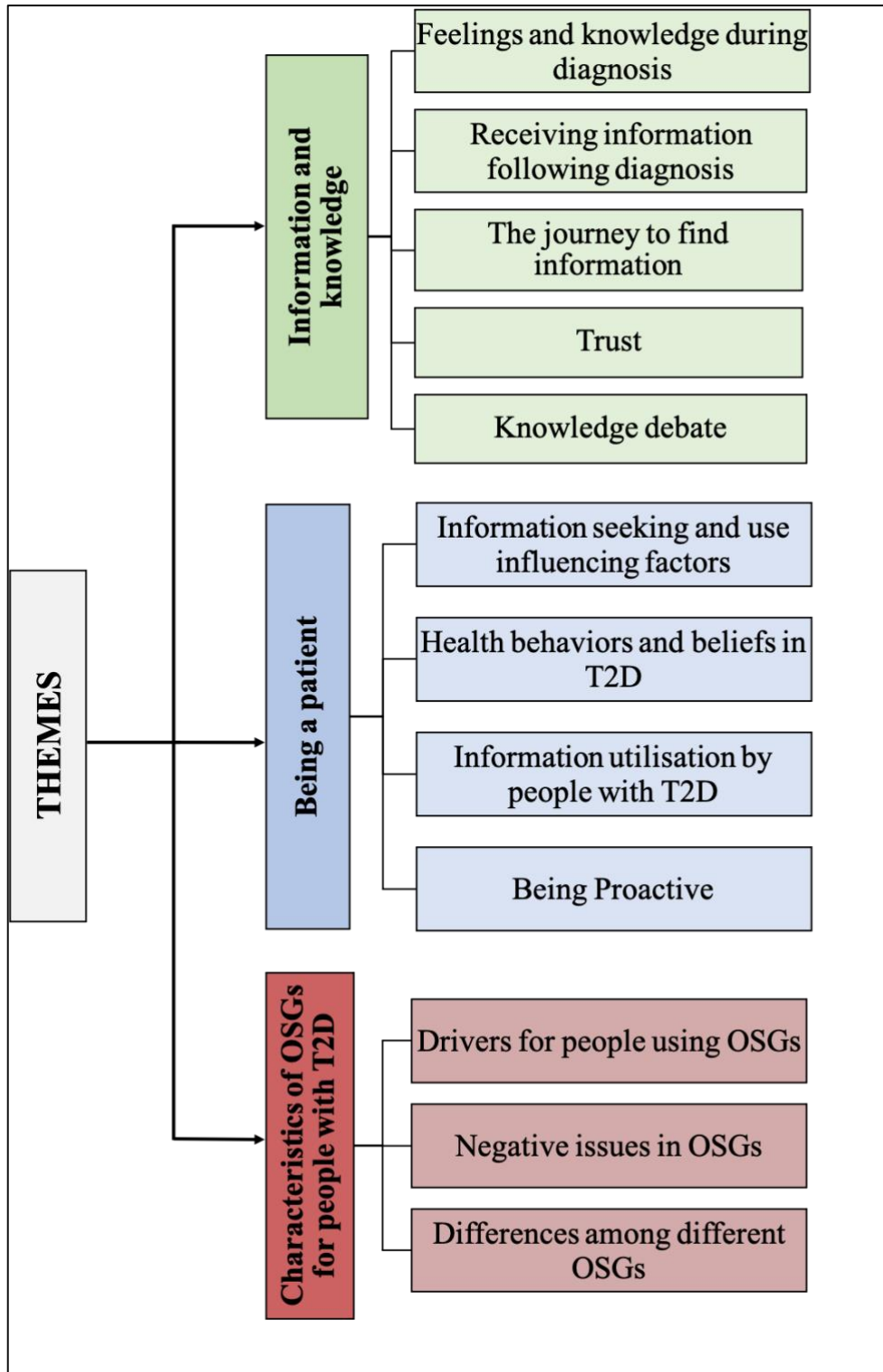
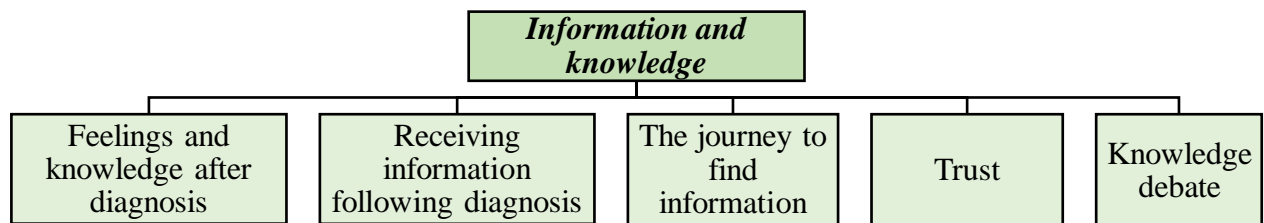


Figure 5.1 Map of the themes and subthemes identified through thematic analysis of the interviews.

Each theme and subtheme will be discussed in the following sections, with quotations from the interviews as supporting evidence.

### 5.3.2.1 Information and knowledge

The diagnosis of T2D created an information need for the participants, which they then looked to fulfil by seeking and navigating various sources. This theme concerns participants' need for information and how they responded to it. Figure 5.2 shows the subthemes within this main theme. The subthemes are discussed in the following subsections.



**Figure 5.2 Subthemes of the theme ‘Information and knowledge’**

#### 5.3.2.1.1 Feelings and knowledge after diagnosis

Initial reaction to the diagnosis might influence how a patient perceives the condition, seeks information, and manages and controls it. Several participants stated that the diagnosis made them feel shocked, angry, scared, worried and disappointed. Many of them had not expected to have diabetes; therefore, the diagnosis surprised them and resulted in negative feelings:

*“[I was] so shocked. I thought I was eating healthily” (Mary)*

*“[I felt] shocked! Complete shock and negative” (Sarah)*

Previous negative knowledge of, or experience with diabetes heightened such negative feelings for a number of participants. This knowledge was mainly about the progressive nature of diabetes and its potential consequences (e.g. amputation, kidney failure). As well as knowledge about diabetes, some participants had misconceptions/misunderstandings about

the nature of the condition. For example, several participants believed (either from previous knowledge/information they received from their HCPs or from information they obtained after the diagnosis) that they would inevitably have to inject themselves with insulin in the future. Others, however, thought that being diagnosed with T2D was their own fault (e.g. as a result of following an unhealthy diet or from being inactive). This, coupled with misunderstandings of, and inadequate knowledge about, the condition, made them more worried after the diagnosis:

*“The diagnosis just hits people in the face and it’s like Oh my god, I have got T2D! Why? How? What I have done wrong in my life to get it! And they have always been told ... you are going to end up injecting insulin which is what I was told at the beginning” (James)*

*“Most of the things I read or heard about [diabetes] were negative” (Sarah)*

Experience of family members with diabetes also contributed to these negative feelings:

*“I was really upset because my dad had been diabetic and he had died young. So, I was frightened ... I felt disappointed in myself. Like it was my fault because you are told that diabetes is your fault” (Catherine)*

Sadness about previous experiences with diabetes was linked with irritation. For example, a number of participants expressed sadness about how diabetes had affected their parents’ health; they then showed how they were irritated with their own diagnosis. The participants mostly used the word “shocked” to describe how they felt when they were diagnosed with T2D. Reading about diabetes complications increased the participants’ negative feelings about their diagnosis of T2D:

*“My mum has had diabetes quite a few years and she had kidney problems, so I felt quite scared, I suppose, and negative” (Sarah)*

*“[Reading about] the complications, the amputations, the loss of sight, the kidney problems ... if you don’t take care of it, that horrified me. I think probably the fact about losing limbs was the most part [that horrified me] ... it was a physical fact that you know that you could lose a foot or a leg or sight because of this that terrified me” (John)*

For other participants, the diagnosis made them feel isolated. This feeling was mainly because they had not expected to be diagnosed with the condition and suffered a lack of social support. They explained that they did not know people with the condition with whom they could talk:

*“I was absolutely horrified and I felt like I was abandoned immediately into an ocean ... they [the HCPs] gave [me] the most devastating news probably that I have ever had about me personally, healthwise” (John)*

*“I’m just a bit alone with it. You know, sort of, yeah, I didn’t know anyone else to talk to about it. So, sort of isolated with it” (Catherine)*

Anger was also reported as a common emotional reaction following the diagnosis.

Participants had different reasons for feeling angry. Some were angry at themselves because their lifestyle had led them to have diabetes. Others, however, were angry because of how people with T2D were perceived or because their HCPs did not support them. A number of participants stated that they used this anger for their own benefit:

*“[I] was angry and disappointed more with myself than anything and then afterwards and since really have been more determined to get myself in the best position possible” (Harry)*

*“[My HCPs were] making me so angry that I am determined to prove them wrong!” (Lucas)*

*“[People with T2D] are already fighting their battle to do anything to make themselves better because [HCPs] think they are going to fail and that’s the message that is handed out and it made me quite angry and maybe after we have done success story threads on the forum, people have been like 5, 8, 10 years diet controlled. You said that was something that isn’t the truth.” (James)*

On the other hand, previous experience with diabetes (such as in the form of gestational diabetes or family history) helped a number of participants to have less negative reactions to the diagnosis. This was mainly because they were aware that they had a greater likelihood of developing T2D, and hence they expected it to happen to them. Having other serious health conditions or contributing factors to T2D (e.g. obesity) also contributed to a less negative reaction to the diagnosis:

*“It wasn’t a shock. If I’m honest, I was kind of expecting it ... It was more of a shock when I was [diagnosed with gestational diabetes] which was back in the 1980s. Good chance that later in life, there’s a good chance you might get T2D ... so I’ve always, I guess, been waiting for the other shoe to drop, you know” (Daisy)*

*“[I was] not completely surprised but upset ... my mother had T2D, I knew I was at risk ... I knew there was some risk, I would get it because there are genetic factors in Type 2 ... I knew it might happen someday” (Emily)*

*“To be honest, I’ve got other conditions as well and when they told me about diabetes, it was just like, fine” (Jessica)*

*“I was very fat and morbidly obese and I guess I believed that [if] you’re fat and lazy ... you get T2D stuff ... And since actually going back and looking at my records, I discovered that in 2004 I had a pre diabetic HBA1C” (James)*

Other participants perceived the condition less seriously because their HCPs downplayed the diagnosis. Therefore, their reaction to the diagnosis was moderated by the HCPs, and the diagnosis did not affect them emotionally:

*“I wasn’t particularly worried about it to be honest, I mean the doctor wasn’t worried, so I wasn’t” (Elizabeth)*

Most participants had limited, or even no knowledge about T2D at the time of their diagnosis.

This lack of knowledge created an information need for them, as the following quotes illustrate:

*“I didn’t think much about it, I didn’t know much. I didn’t know nothing about diabetes at that time. I knew that it was just one of the illnesses/sickness ... [just] go to the doctor get the medication, no matter, you’re sorted, nothing else to do” (Oscar)*

*“At that time, I was a bit lost ... I was on the Internet when I got diagnosed finding out about what I should look out for, what would help me” (John)*

*“I didn’t really know, I didn’t know a lot about it” (James)*

The subtheme of feelings and knowledge after diagnosis of T2D reveals that most participants were surprised by their diagnosis and reacted negatively to it. The predominant emotional responses were shock, sadness and irritation, and these were sometimes connected to other experiences of T2D; for example, previous experience of T2D sometimes mitigated

the negative reaction to their own diagnosis. The emotional responses were also linked to knowledge about the condition and its potential complications for some participants, with lack of knowledge increasing negative feelings. Participants' knowledge about the condition at the time of the diagnosis was usually limited, which not only contributed to a negative emotional response to the condition but also created an information need. Participants' emotional reactions to the diagnosis is further explored in Section 5.4.2. The next subtheme looks at how HCPs attempted to fulfil this information need.

#### ***5.3.2.1.2 Receiving information following diagnosis***

Participants' perceptions of the amount of information they received from HCPs following the diagnosis varied. However, most of them repeatedly expressed their need for more information and support from their HCPs at the time of the diagnosis. For example, some participants were informed about the result of the diagnosis without being provided with any initial information:

*“It was literally a phone call saying, you know, HbA1c has given us a pre-diabetic result. You need to lose some weight. Thank you very much ... I think it was actually the receptionist who just phoned up and you know, gave the spiel ... It was just literally a courtesy phone call [with] no information”*  
(James)

*“They ring me to say that you're diabetic, Type 2. So, my GP was on holiday, so I had to wait till he came back. But they gave me a prescription for Metformin with no information. So, three weeks later saw him, he recommended a course. And that was it”* (Isabelle)

*“Initially nothing because the receptionist just told me on the phone, and then there's a gap of about two or three weeks and then the information was a leaflet with, it might have been, I think, the Eatwell Plate”* (Catherine)

*“[I was given] absolutely nothing. They sent me on a diabetes course which was weeks later”* (Mary)

When they met their HCPs, many of the participants commonly reported that they received limited information in the form of a leaflet about diet, which they perceived as inadequate:

*“I was given a very bad recyclable picture of the Eatwell guide and that was really about it ... its general population diet advice which is, I am no longer part of the general population, I have just been diagnosed T2D ... it's you've got T2D, take these pills, eat on the sheet and see what happens”*  
(James)

*“I was given an A4 sheet of paper which should be photocopied many times telling you that I should be eating nine portions of brown carbs, that kind of food ... I haven't eaten that amount of carbohydrates in a decade!! I screwed up the paper and threw it in the bin and I left the surgery!”*  
(Alice)

*“I was told, take these tablets, and avoid sugar, and the Eatwell Plate, and exercise more, even though I was exercising fairly well anyway, and lose weight, and the usual standard advice, which was done quite quickly”* (Sarah)

*“[I was told] to cut out sugar and take these tablets and that was it.”* (Jessica)

For several participants, there was a delay between the initial diagnosis and receiving more practical information from their HCPs. This led them to seek information from other sources, including OSGs. By the time they saw their HCPs, a number of participants had already obtained information from other sources, which made the information provided by HCPs unfavourable, as highlighted in the following quote:

*“They gave me information on diet ... very limited information ... I was a bit lost ... then I got offered a DESMOND course about 8-10 weeks later ... because the course was so late, I was on the Internet finding out about what would help me and by the time I had come to the course I had already had a lot of information ... The information they gave [on the course] wasn't what I was aware of or not completely aware of ... so I questioned some of it ... I went my way and I think I left the course in its way and I am happy I did”* (John)

The information acquired between the time of the diagnosis and the receipt of official information also led to tensions between participants and their HCPs. This was because the information given in the official sessions/courses did not align with the information participants found from the Internet. As a result, several participants refused the information provided in the sessions or even withdrew from them:

*“They sent me on a diabetes course ... they [those on the course] were talking about having jacket potatoes. I said, excuse me: jacket potatoes raise your blood sugar levels, they said how do you know?? I said because I test! [she said] YOU TEST?? YOU ARE NOT SUPPOSED TO TEST! And I did not go back. [I knew that] from reading the forum. I went to the forum before going to that course ... it was supposed to be once a week for six weeks and I went to one-half of one morning.”* (Mary)

*“[HCPs] wanted to refer me for the DESMOND course. I’ve heard some very, very bad things about the course and I had already joined the Low Carb Programme and gone low carb instead ... the DESMOND course at that time was very anti low carb and I thought that would be quite unhelpful to spend a day with a room full of people who are telling me to eat more [carbs]” (Emily)*

*“I’ve been to one of these [courses] and what an absolute waste of time, money and effort. Shockingly poor ... The Eatwell Plate was presented ... things like: have a snack, a banana. Well, bananas got about 30 carbs in it, I wouldn’t eat them” (Isabelle)*

When participants were given information after the diagnosis, it mostly took the form of dietary information. This also contributed to tensions between HCPs and most of the participants. The information that they were given recommended that newly diagnosed diabetics should follow a balanced diet that included proteins, fruit and vegetables, and starchy carbohydrates. This advice was unfavourable to many participants, especially after they had gathered information from other sources. They discovered that cutting out, or reducing, the amount of starchy carbohydrates had a significant impact on their management of the condition. The time it took to discover this varied among the participants. Some of them followed the advice given by the HCPs for a long time (i.e., a few years) before discovering this information:

*“It took me quite a few years ... before I realised that I need to stop eating carbohydrates ... but the problem was with diet, it was really essentially the wrong information; because what I was advised to do is eat a balanced diet and it turns out in that respect that wasn’t true” (Andrew)*

*“The [diet] advice she gave me [two years ago] was the wrong advice as a way to do it ... the method that she talked about wasn’t working for me ... I tried it really hard [for two years]. I did lose some weight and I did reduce my HbA1c a bit, but not enough” (Sarah)*

Several participants reported that their HCPs informed them after the diagnosis that the condition is progressive and that patients have very limited control over it. This gave them the impression they would not themselves be able to take action that might improve their health status. However, this did not stop most of the participants from seeking information and trying alternative methods to control and manage the condition, as the following quotes illustrate:



*“[I was told that] it’s progressive you can’t do anything about it” (Mary)*

*“The point of view was it will get worse. [The nurse said] we can do our best but ‘it is a progressive condition’ was the message I had. You can try and sort of slow the progression, but over time you will end up on insulin was the message!” (Sarah)*

*“[People with T2D are] often told it’s a progressive chronic disease you know, you’re going to end up injecting the insulin, which is what I was told at the beginning” (James)*

For others, although the information from HCPs was helpful, it was provided at a later stage, when they had already obtained the information elsewhere:

*“It was to really just verify some of the things I’ve read myself. So, it was basic [information] on the cause, how to manage it a little bit and the links with diet and exercise. It was helpful, you probably found it more useful on the day [of the diagnosis] because I was more quite excited to do something about it. So, I got information myself” (Harry)*

A few participants, although still reporting that they were provided with limited or no information at the time of diagnosis, were encouraged by their HCPs to join OSGs as a source of information. They stated that this piece of information was very useful, and they felt grateful at the time because it was a starting point for them, as the following quotes explain:

*“I just was told to avoid sugar and limit carbs, not extreme, just slight lowering of them ... I was told to join [an OSG] which was the best piece of advice I got given” (Sophia)*

*“I got diagnosed on a phone call and then they said look at this forum” (Isabelle)*

In conclusion, most participants found the advice provided by their HCPs following the diagnosis to be limited and the information they received to be untimely. The delay between diagnosis and the provision of information by HCPs led many participants to find other sources of information. This, in turn, led some of them subsequently to refuse the information provided by HCPs. Others followed the advice from their HCPs for a few years until they discovered that this information was limited. The evidence indicates, therefore, that the participants were keen to receive information, and that when they perceived a lack of

information from their HCPs, they found other sources. The participants also revealed that they welcomed information accompanied by social support, both at the time of diagnosis and subsequently. Participants' opinions about information provision following the diagnosis is further discussed in Section 5.4.2. The influence that OSGs had on that relationship that patients had with HCPs and the health care system is also explored in further detail in Section 5.4.5.

### **5.3.2.1.3 The journey to find information**

As discussed in the previous subsection, participants' unmet informational needs after they were diagnosed with T2D created a knowledge gap that they needed and wanted to fulfil. This knowledge gap, and the need to fill it, arose because participants were provided with little or no information, or because the information they received was not useful:

*"I saw a dietitian, but he didn't really answer my questions. That was just the Eatwell Plate again"*  
(Catherine)

*"I was obviously not going to get any help from the HCP, so [the Internet] seemed to be the obvious route to go down"* (Elizabeth)

*"To be fair, I was already eating the Eatwell Plate, so there is no point in me in doing that. I got being diabetic for eating that. So, I went searching and I found the forum"* (Mary)

*"[When I] did not get very regular appointments with the HCPs, I [started] looking it up online"*  
(Sally)

However, several participants started their information journey even before the formal diagnosis. They generally felt that they were going to be diagnosed with diabetes, so they wanted to learn about the condition and how to deal with it:

*"[I started looking] a few weeks before I was diagnosed because I thought: ooh no! my glucose tolerance test is coming up"* (Alice)

*"I had already started looking before the actual diagnosis confirmation, I started searching upon getting the first HBA1c result rather than waiting for the second one to confirm it"* (Lucas)

When the participants started their journey to find information, they were mainly looking for general information about the condition, medication, diet and how other people with T2D coped with diabetes. For most participants, the Internet was the starting point to fulfil this need. They used search engines to navigate through different websites about T2D. Some of them found the OSGs directly and started browsing them. Several participants explained that they were selective about the information they first found. This selectivity made them prefer one online source of information over another. For example, Mary and Alice explained that, when they first started searching for information on the Internet about T2D, they found one of the OSGs. However, after browsing the OSG, they decided to look for another source of information because the OSG contained unfavourable information:

*“I searched and found [the OSG] and I said that’s what I’m doing already, and you think there must be something better than that and then I found the [other OSG]” (Mary)*

*“I searched ‘diabetes’ and I found a forum and went there and I remember looking at their recipes and what you can eat and what you can do, thinking F\*\*k that! because I could never have eaten any amount of carbs they were suggesting. And then I kept looking and came to the [other] forum, and there were people talking sense on there!” (Alice)*

Further discussion about why some participants favoured one OSG over the others, and how they switched from one to the other, is presented in Section 5.3.2.3.3.

Most participants reported that, when they found their preferred OSG, they spent many hours browsing and reading the OSG before posting. Participants explained that success stories posted by other members made them interested in joining such groups. The stories gave them hope that they could achieve what other members achieved, as indicated in the following quotes:

*“[After reading the success stories] you suddenly started saying, oh yeah this is actually doable and let’s do it! Let’s try it! If a whole lot of people could do it and they have kind of success, why I couldn’t do it! [Knowing that] was really powerful” (James)*

*“[Reading about the success of other members] gave me the sense that there are other people that were successfully managing it. It wasn't the slippery slope down to amputations. Practical advice on how actually to do it” (Sophia)*

In addition to members providing knowledge and experiences on the OSGs, they also directed the participants to other sources of information such as articles, books, and websites. This helped the participants find the appropriate sources of information at that stage, as some explained in the following quotes:

*“People [on the forum] are giving links to other websites and other sources of information and it's like a crossroads ... you don't agree with it all, but at least it's a shortcut to something amazing, then you can springboard from both sites into other ones; and it was just like very useful and helpful indeed” (Alice)*

*“My HCP gave me a prescription for Metformin with no information. So, I started to read a book that someone on [the OSG] recommended, one of the best books I've read. I started to understand [T2D] ... there are lots of really interesting members, lots of people that were happy to invest time with you, you know, you can try this, try that” (Isabelle)*

*“I just googled, and it was straight to the forum. And that's what I used, the recommendations from the forum to which YouTube things to watch and things like that. So, I used that” (Catherine)*

The participants valued the suggested information sources because they believed that they had been useful for other OSG members and had helped them achieve their goals. As well as the other sources of information, the participants received information designed for new members from their peers and OSG moderators, which helped them navigate through the huge amount of information on the website. This mainly consisted of basic information about the nature of T2D, how it was expected to influence patients' lives, what changes they were supposed to make, the role of diet in managing and controlling the condition, how to interpret blood test results, and their legal rights in accessing health care. This information provided them with the basics and acted as a catalyst for them to browse the OSG and start their information-seeking journey:

*“When you join the forum, you get tagged into a member, they're called [member username], she will send you the format, you know, this is where you can find this information. You know, this is how*

*many members are still with it, this thread might be useful. And you know, you're given a whole list, it's, you know, where you can find the information that you need" (Isabelle)*

*"I registered with them [the forum] and they sent me a pack [of information] and just took it from there" (Elizabeth)*

The initial information exchanged in OSGs led many of the participants to search about specific topics in other sources. When they read that other members had benefited from something, they started to search online to know more about it and whether it would apply to them:

*"I might click through a couple of different threads about the Libra and then I went to their webpage, and I found out that I can actually buy it ... I then sort of searched online in other places and try and find [about] it" (Jessica)*

The participants' background contributed to the type of information sources they were interested in. Most participants with a postgraduate degree looked at scientific sources to build on the information they first read in the forum. They were also more interested in the scientific threads in the OSGs, as indicated by the following quotes:

*"A lot of people post lectures and conferences, that's why I went to my first conference a few months ago as a result of that ... I'm really keen if I see a post that's about research with anything to do with diabetes, I tend to read it and maybe watch the videos of the presenter from the conference or I'll read the academic material" (Sarah)*

*"Some of it did include new stuff. I was very much interested in the links to the research, because of my background" (Emily)*

*"And then I became more and more interested in the studies, and the evidence" (Alice)*

However, some participants found that OSGs and online communities were not appropriate for them; therefore, they were not interested in joining them. This was mainly because they felt that they were too old to join such groups:

*"I was older and it wasn't a natural place for me to be. I think my youngest son for him it would be like living and breathing, but for someone over 60 it's not" (Sarah)*

Instead of initially joining online communities, some participants joined a 12-week structured online course that introduced them to the nature of T2D, LCHF diets and other practical information about the condition. The platform hosting the online course contained a small OSG only for users registered on the course. Accessing and engaging in the small OSG as part of the course introduced them to being part of an online community. As a result, they then joined a larger, open OSG when they finished the course to seek more information about the condition, as explained in the following quotes:

*“It wasn’t natural to stay with the [small] forum, because when I completed and succeeded [the course], it was more taking part in the [big] forum, it was more interesting, there were more people on it and it was more about what I wanted to find out about” (Sarah)*

*“I couldn’t get some of the answers on the [small forum] that I was looking into further down about the research and things as easily. And so, the [big forum] was much better from that point of view” (Emily)*

The participants who joined the structured course did so because it walked them through basic information about diabetes during their first weeks of living with the condition. The course presented the information in different formats (e.g. video, text, images), which made it easier for them to follow. It also provided them with emotional support and encouraged newly diagnosed people with T2D with ways to cope with the condition, which they found helpful:

*“I found the positive reinforcement [in the course] very helpful. And to keep me going when I hit a mental barrier or got a bit fed up about having to do this for the rest of my life, possibly” (Emily)*

Others, however, waited for some time (e.g. up to several years) after the diagnosis before starting their information journey. Having been officially diagnosed and given limited information, they followed this information for a long period of time without looking for other sources of information because they thought the official information was the only approach to the treatment of the condition. During this time, their management of the

condition was normal. They had limited improvements but still struggled with the condition and did not reach a stable status. For several reasons (which are discussed in Section 5.3.2.2.1), they eventually started to look for information on how to manage T2D. They then realised that their knowledge about the condition was limited and that there were alternative methods to controlling and managing it, as the following quotes illustrate:

*“[For four years] I was too busy [to look for information], I didn’t fully understand the implications. I thought I was on the right track with [the standard information from the HCPs]. It took quite a number of posts to realise: what I was doing is wrong and it took me a number of posts to find out the way forward” (Andrew)*

*“Up to the 21 months’ time from diagnosis ... I just went along with the standard advice but then I discovered the forum and it was then that things started to change” (Sarah)*

By investigating the subtheme of the participants’ journey to find information about the condition, it is possible to understand why, when and how the participants began this journey. There was not a single path that all participants took. Most, but not all, started the journey before or directly after the official diagnosis; a few began their journey long after diagnosis. Some used an OSG for some time before switching to another because of the type of information exchanged. The findings suggest that participants who started their information seeking journey at, or soon after, diagnosis had a better understanding of their health status and the available treatment options, as well as practical information on how to treat their condition. This is consistent with the findings of a previous study that reported patients who engaged in exploratory searches having a better understanding of “what is ‘normal’ in terms of the manifestation of their particular symptoms, the variables they should be tracking, and the effects on their lifestyle and medication adherence” (O’Kane, Park, Mentis, Blandford, & Chen, 2016, p. 479). The present study further adds to the literature that early exploratory information seeking contributes to improving health literacy, especially regarding contradictory practical information. The information seeking in early stages of the condition helped participants to learn “what others were doing” and how it impacted their health status.

This included learning about practical and controversial information that helped other OSG members. Different uses of OSGs and user behaviours is further discussed in Section 5.4.4. The next chapter also discusses the information journey of the members and participants of the study (see Section 6.2).

#### **5.3.2.1.4 Trust**

Trust played a major role in how the participants perceived the information they were provided with or found in different sources. Questions arising from the first study included whether, and how, the OSG members assessed the credibility and trustworthiness of different information sources. In this subtheme, participants mainly expressed how they trusted or mistrusted the information either provided to them by their HCPs or found on the Internet.

Some participants suspected that pharmaceutical and food companies influenced the information provided by HCPs. They queried why, if the information given was ineffective for most people, it was still being given. They believed that this was because the companies profited from people's consumption, and hence that the companies endeavoured to change the public perceptions and keep people consuming. This affected the way some of the participants perceived the information that was provided by their HCPs, as the following quotes indicate:

*"If I know [the information/treatment given was not effective] why doesn't everybody else know it? So, why don't the doctors and nurses know? It's because there's big Pharma and big Food [companies] behind all this ... they do it for the money, they don't care about anybody's health. They just want to make more money" (Mary)*

*"There's an awful of defence from the pharmaceutical industry wanting to push their drugs, there's a lot of problems from food manufacturers wanting to push their carbs and their sugar. So, there's a lot of financial pressures as well to maintain the status quo. And make us all look like raving lunatics with a fat diet" (Sophia)*

*"Everyone is supporting them to kill you, you know, you can't sue them. So why should they take the risk of telling you" (Oscar)*



The belief that different companies influenced the information provided to people was not limited to the information given by HCPs, but also included information given by OSGs. Several participants explained that they were suspicious of the information on some OSGs because the OSGs were sponsored by companies. They did not, therefore, trust the information presented on the main websites of these OSGs, that provided by the OSG moderators, or even information that was exchanged by ordinary members:

*“Pharmaceutical companies don’t like that! they pay money! I mean [name of an OSG] is sponsored by [name of a company], so they’re not going to go against their sponsors and say you shouldn’t eat this! So, they are not going to go against because it is where they get their money from” (Mary)*

*“I think food companies tell [name of an OSG] what they can and can’t talk about and what the problem should be. I don’t think they tell that to [name of another OSG], because they don’t” (John)*

Participants also believed that HCPs provide the wrong information for people with T2D because the health care system had spent massive resources on research in previous decades and were reluctant to accept that some of the information was ineffective:

*“The government have got their ridiculous nutritional guidelines and to turn around and say: actually, we’ve been getting it wrong for 50 years, it will be a massive humiliation, so they have to do it incrementally” (Sophia)*

However, another participant observed the spread of this conspiracy theory on the OSGs and argued that it did not make sense. He believed that the health care system provided the right information and he trusted it as a favourable source of information:

*“So, there are people on the forum who are empty, everything is conspiracy theory. Well, my view is, has always been that the NHS be a bit foolish to give advice that leads to problems is designed to try and reduce people’s risk because ultimately they’re gonna have to pay to fix it in the future ... people get very suspicious about big Pharma because ultimately they’re gonna profit from your problems, but here the NHS doesn’t work that way because they give you advice and the ends of your internal operations on your eyes is not you paid, but the NHS. So, I do tend to use the NHS as a backstop for information” (Harry)*

Participants in this study who believed in the conspiracy theory tended to be much older and have a lower educational level than those who did not believe in it.

When speaking about trusting HCPs, several participants explained that when they used other sources of information, especially OSGs, they realised that the information given by their HCPs was outdated. This led to them perceiving their HCPs as having limited, and no longer relevant, information about the condition, in comparison to the sources of information they had found on the Internet. As a result, they lost trust in the information their HCPs provided, as the following quotes explain:

*“[HCPs] are so out of date ... they would give me information and I’ll come home and I’ll check it out to see if I agree with it” (Mary)*

*“I took the hint when my GP told me blatant (but generally accepted) lies about statins, lipids and salt” (Lucas)*

*“I honestly believe [that when] I went to the doctors [I] trusted them and now I don’t trust them because they told me information that doesn’t fit me, that doesn’t work for me” (John)*

*“I knew some of what she [my HCP] was saying was not supported by current research ... I read about it” (Emily)*

*“I don’t trust my health care professional .... I don’t have a lot of faith in health care professionals ... the information being given to people, it’s making them sicker rather than healthier. I think it’s almost criminal, the lack of knowledge, and that lack of choice, and awareness, people are being given” (Sophia)*

*“My trust was completely in the medical profession at that time and now is completely changed ... because of my research and the diabetes and finding out how little they know about diabetes, and yet they’re giving the wrong information, wrong advice, killing us” (Oscar)*

Others made a point of referring to the education and training of their HCPs. They believed that the reason why the type of information and treatment options provided by their HCPs were outdated was because the HCPs were not equipped with the appropriate knowledge. This was attributed to two main reasons. First, the participants believed that HCPs had received their training/education a long time ago and had not been provided with recent personal development training. Second, they believed that, because their HCPs were General

Practitioners, rather than specialists in treating T2D, they did not know about the appropriate diets and alternative treatment approaches. It was argued that HCPs did not accept patients' suggestions for alternative approaches to controlling and managing T2D because these approaches were not familiar to them:

*“The NHS, the training of the doctors, is very, very behind the times with modern research ... and really fixated on disproven things” (Catherine)*

*“GPs are general practitioners, and if, unless they choose to update their knowledge about diabetes, they probably have had no training since their initial training and things may have done a long time for some of them. They are just unaware, particularly, about Type 2 alternatives out there. The ignorance is astounding” (Sophia)*

*“If something comes along that completely undermined their teaching, they can't accept it” (James)*

*“[People on the OSG] have been living with it. They are not sitting behind a desk as our nutritional training many years ago” (Mary)*

*“[HCPs] have been indoctrinated by their training; and different health conditions should be treated with different diets; but they don't do that; they just roll out the standard diet” (Alice)*

*“That's the issue, doctors [and] their trainings ...very, very few interested in doing something different and helping.” (James)*

Other participants commented on the approach that HCPs use to treat different health conditions. In their view, HCPs tended to use medication before trying to manage and control the condition by other means (e.g. diet control). For this reason, some participants did not trust the treatment and information provided by HCPs:

*“I don't really trust medical convention on the whole about taking tablets all the time. I don't trust that. Yeah, I just found that you're better off managing something yourself. Otherwise, you just get given tablets” (Catherine)*

The second issue of trust discussed by participants concerned the information provided by other members of the OSGs. Participants varied both in how much they trusted this information and in how they evaluated it. Some participants stated that they did not believe everything exchanged among members on the OSG. They frequently asked other members about the source of their information and they conducted their own searches about

information other members shared. This was particularly the case if it was new information being shared with them, as the following quotes illustrate:

*“I don’t believe everything I read online ... some of it, I kind of research myself when I read something, and I put up a webpage, and I just check it out. But it depends what they’re talking about as to how important it is to self-research it, you know” (Jessica)*

*“I would always ask for the research links if they say they’ve read something. So yeah. If it’s confirming something I already know quite a bit about, I might not do all of that. But if it’s in areas where there hasn’t been a lot of previous research, or I haven’t read about or it’s something it’s challenging what I think, I would go and check it” (Emily)*

*“You take it [the information] with a pinch of salt, thank them for the advice and information or make a note of it, but being careful where it came from” (Oscar)*

*“But you do have to take it with a pinch of salt” (Harry)*

*“[I] never, never [trust online information], I always double check it. I don’t take anything from a stranger on the Internet on trust” (Alice)*

While some participants treated all information shared on OSGs with caution, others explained that their trust in the information exchanged on OSGs depended on the member who shared it. They would build their trust with members based on the reliability of that member’s information. Initially, they would check the information a member provided on the OSG against other sources. However, if their experience with that member proved to be positive, they would, over time, build a trusting relationship with them. Participants were less likely to trust new members over old members. A few reported that they were suspicious that some new members might have commercial interests and provide misleading information:

*“You get to know who the people are, who obviously have a better medical knowledge. You sometimes get people going on who are new members who are trying to sell something. So, you have to be careful with that” (Catherine)*

*“There’s some people they put good quality links to their opinions or their sources of their information. Or what I’ve researched myself having heard an opinion matches that, that person, they gave me accurate information. When that happens, time after time, you start to trust it. Equally, so there are other people that post things that you kind of think, really? And you go away and check it out and think have you even got a clue what you’re talking about. So, the next time they say something, you can think really last time you were way off. So ... it depends where it comes from” (Sophia)*

*“You do get trusted members who you’ve known for a long time and obviously you’ve been more inclined to trust what they said than somebody who just appeared” (Sarah)*

*“If I recognise one of the posters that I think is good, you know, for information, then I’d more like to look at them” (Catherine)*

Other participants explained that they found members who posted about their progress and had achieved their goals to be trustworthy:

*“For those members who list their HbA1c and Lipid numbers histories for more than one year – then, yes, I trust their advice. But only as it relates to their own personal situation ... those who have achieved either full or partial remission of T2D over months/years are the most convincing” (Lucas)*

Although some OSG members had positive experiences and shared information about them, some participants still thought that this was not convincing enough to accept the information they provided. They were worried about the long-term consequences of the member’s experience:

*“I don’t listen to everything that’s written down because some people have got opinions based on their experience, which doesn’t necessarily mean that they understand the long-term impact of certain things” (Harry)*

Participants varied in how they used the information provided by their HCPs or the health care system to verify the information exchanged in the OSGs. Whether they used or ignored the HCPs/health care system depended on how trustworthy they found them. Participants who trusted these sources considered the HCPs/health care system as a reliable source of information to confirm or disprove what they had read on the OSG. Those participants who did not trust them were also suspicious of some online sources because they believed they might have been influenced by the official point of view of the health care system, as the following quotes explain:

*“I do check other sources – though those other sources are probably influenced by the same doctors and dietitians” (Lucas)*

*“[After I have been given information on the OSG I try] to find it on the NHS website. On a formal website somewhere and have a look, or in a reference book or something ... I haven’t overwritten the doctor’s advice based on the forum” (Harry)*

*“I trust the information on there [OSGs] ... if it was a possible bad outcome, then maybe look elsewhere on the NHS website or something, but see what else is on there. But [usually] no” (Daisy)*

One participant reported that he relied on other members to either confirm or disprove information on the OSG. He explained that he used a collaborative approach to evaluate a given piece of information. He would look at how many members agreed or disagreed with that information and then judge it:

*“What I did was first try to see in the forum how many people? How extensive this was? I was looking for numbers ... when I posted and inquired some things ... I sometimes get a conflicting answer, whereas sometimes that answer didn't make any sense ... what I did was try and go just on the weight of numbers, so if I got 20 responses, if 18 of the 20 are all saying the same thing, I then began to say, well that sounds like it's probably believable” (Andrew)*

In summary, the subtheme of trust provided insights into how the participants perceived the information provided to them either by the HCPs or via their OSGs. The findings suggest that most participants tended to trust information providers who offered a range of information about all the approaches to controlling and managing T2D; thus, HCPs were trusted more if they provided information about alternative approaches. Thus, participants were not content simply to receive information; rather, they wanted to receive a range of information so they could evaluate it and check sources against each other. When such a range was not forthcoming, many participants became suspicious about the reasons why. Information gathered from the Internet increased the likelihood that HCPs would be perceived as having commercial interests or out-of-date health knowledge. Furthermore, OSG websites that supported a particular control and management approach over other approaches were likewise distrusted by many participants, and this was one reason why participants shifted from using one OSG to another (as Section 5.3.2.3.3 explains). These findings confirm those of Sbaffi and Rowley (2017) who reported that the objectivity (being unbiased and impartial) of online health information is just as important the trustworthiness and credibility of the information provided.

The findings also indicate that most participants would build a trust relationship with other OSG members over time and based on their online activities, accuracy, and progress in controlling and managing the condition. Initially, participants tended to be suspicious of sources of information; however, as they evaluated not only the information but also the sources of that information, they came to trust certain sources over others. In short, trust was a complex dynamic that related both to the information itself and to the providers of that information. The trustworthiness of information is discussed further in Section 5.4.3.

#### ***5.3.2.1.5 Knowledge debate***

As found in the previous study (Section 4.3.2.3), this subtheme captures the issues over which participants had conflict with their HCPs and how the use of OSGs contributed to their understanding of such issues. The interview data confirmed the earlier findings. Many participants reported that they had arguments with their HCPs regarding certain approaches to T2D control and management. In particular, they had debates regarding the healthy diet that people with T2D should follow. They questioned the diet plan recommended and prescribed by their HCPs. Some of them had followed the diet plan before the diagnosis, and they believed that it was because of the diet that they had diabetes (the Eatwell Plate), as the following quote illustrates:

*“To be fair, I was already eating the Eatwell Plate, so there is no point in me in doing that ... I thought I was eating healthily, the Eatwell Plate is good for you [laughter]. No IT IS NOT. I got being diabetic for eating that” (Mary)*

Most participants believed that the problem with the recommended diet was the amount of carbohydrates included in it. In their view, carbohydrates should be strictly minimised in their diet:

*“The Eatwell Plate for me was presented, you know, like things that: have a snack, a banana. Well, bananas got 30 carbs in it, I wouldn't eat them! Have a third of white pasta. Well, I wouldn't touch wheat pasta, no, no, no” (Isabelle)*

*“[HCPs told me that] I should be eating a portion of brown carbs (slice of brown rice, brown pasta) that kind of food. I haven't eaten that amount of carbohydrates in a decade!!!” (Alice)*

In particular, some participants thought that the Eatwell Plate was designed for healthy individuals who do not have long-term conditions, a population they were no longer part of:

*“It's [a] general population diet advice which is, I am no longer part of the general population, I have just been diagnosed with T2D ... [my] numbers [were] quite [high, so] that the Eatwell guide information probably wasn't going to be that useful” (James)*

Several participants reported that, although they had tried the recommended diet, they had achieved limited or no results. Consequently, they sought other sources of information to know more about the nature of the recommended diet and whether they were the only ones who had not reacted properly to the diet, as the following quotes illustrate:

*“She gave me the wrong advice ... the method that she talked about wasn't working for me! I tried [the Eatwell Plate] really hard. I did lose some weight and I did reduce my HbA1c a bit, but [it was] not enough” (Sarah)*

*“The Eatwell Plate, why does it not work with me? ... so, I kind of wanted someone to give me another diet because the one I was on wasn't working and I just wanted someone to say, that's not the right diet for you. You need to go on ... whatever diets on there ... or tell me that there wasn't any diet out there because I was ill and you know it, maybe here's a way of adapting to it” (John)*

Some participants explained that, when they read on the OSGs about how carbohydrates raised blood sugar levels, they asked their HCPs whether this information was accurate and whether they should eliminate carbohydrates from their diet. They were confused by the conflicting information they received from their HCPs on the one hand, and from the OSGs on the other. Several participants reported that they were unconvinced by the answers given by their HCPs:



*“[My HCP] wasn’t able to answer my questions regarding ... cutting the carbohydrates. And I was just told that carbohydrates are important and fibres are important. And then I asked about fibre and what are good sources of fibre, and he wasn’t able to answer me that either. So, it wasn’t very good at all for anything other than this food pyramid and all of that sort of stuff” (Catherine)*

To rationalise the conflicting information about carbohydrates, participants tried to test their blood sugar levels before and after meals that included carbohydrates. They then monitored the levels over time and concluded that carbohydrates raised their blood sugar levels.

Therefore, they used their personal experience to evaluate information. Most participants explained that they had positive results in controlling and managing the condition after changing their diets:

*“Since I was taking the change in the diet and that, my blood sugar numbers have dropped from being 15 or above to be in between six and eight” (Jessica)*

*“I have changed my whole life, after depression [and] medication. My blood pressure was 180 over 80 or something and I had to be on meds; I’m not on any medication at all! I’m not on blood pressure medication, I’m not on diabetic medication, I do not take a pill, and I had all those illnesses quite clearly! You know, not slightly! I used to see the doctor a lot. Now, I don’t” (Sarah)*

Although participants were able to control and manage their T2D when they changed their diet, several of them reported that their HCPs still underestimated their achievements and approach to controlling T2D. They explained that most HCPs did not want to discuss how they had extraordinarily decreased their HbA1c and controlled their T2D by diet alone, as the following quotes illustrate:

*“[My HCP] is like, what were you have been doing [to achieve these results]? [I answered:] I was on a low-carb diet, so she is like, Oh! that won’t work. So far, you have seen my hba1c half of what it was before and you say that won’t work!! So that’s when I started being, you know, more angry, a bit more forceful with them” (James)*

*“[My HCP] was not interested in seeing me or discussing what I’ve done to make the improvements” (Alice)*

As explained in Section 5.3.2.2.4, after achieving positive control and management of their condition, some participants tried to change the information provided to newly diagnosed people, especially regarding the optimal diet plan they should follow:

*“Public Health when they review the Eatwell Plate a lot of frustration to them about it. [I] never got an answer. Don’t think anybody did. And they just totally ignored all the research links we sent them because they just published the same page again” (Emily)*

Participants elaborated on their concerns about prescribing the diet to newly diagnosed patients and its approval as the recommended diet for people with T2D. In their view, this led to newly diagnosed patients taking the wrong path, and it made it hard for hospitalised people who have diet-controlled T2D:

*“That has a huge impact on what happens when you go into hospital, for example, because eating low carbs in hospital is very impossible, a big concern for members in the forum. What happens when you go into hospital if you get diet-control T2D, because most hospitals, breakfast now is like a buffet carb” (Emily)*

*“With newly diagnosed people, you really have to drive into them: Fat will not make you fat, carbohydrates make you fat, not fat, and it won’t clog up your arteries ... newly diagnosed or even people that have been diabetic for 10, 20 years and they found the forum and they’ve started taking notice, you know, getting their blood sugars down if it’s just amazing, why has nobody told me about this before ??!?” (Mary)*

As the findings of the previous study showed (Section 4.3.2.3.1), many members of the three OSGs had arguments with their HCPs regarding self-monitoring of blood glucose (SMBG). This finding was confirmed in the interview study. Several participants described disagreements they had with their HCPs about SMBG. They were told that SMBG was not useful for people with T2D and were advised to avoid it, as the following quotes show:

*“I asked for a test metre and I was told we don’t give them to Type 2s ... I had two separate nurses tell me that I shouldn’t be doing that, it’s a waste of time and it won’t do anything useful! Which is rubbish” (Alice)*

*“ ‘YOU TEST??????? YOU ARE NOT SUPPOSED TO TEST!’ ” (Mary)*

Most participants reported that they learned about SMBG mainly from the OSGs. Seeing other members on the OSGs using SMBG as a tool to monitor their control and management of the condition encouraged the participants to use it as well. They also learned practical information about SMBG (e.g. how to use self-monitoring devices, where to buy them, and how to interpret the results), and they obtained emotional support to overcome their fear from using SMBG devices, as the following quotes indicate:

*“That was off the websites as well, the forum. Everybody on the forum tests” (Elizabeth)*

*“I got a test metre after I joined the forum because I didn’t even know you could buy test metres at that point. And as soon as I read that on the forum” (Alice)*

*“I was scared to death [to use a self-monitoring device]. I mean, I didn’t know how to use [it], couldn’t work it out, and I remember thinking: why am I doing this?! why am I doing this when the diabetic nurse does not say I should, or I need to? ... I had to go on to the forum and find out, did it hurt ... I’m not sure if I could have launched off that feeling without the forum” (Sarah)*

After using SMBG devices to monitor their control and management of the condition, most participants found that it was a useful tool for making them aware of their blood sugar levels and what influenced those levels:

*“I was really quite motivated to, to make change and it is really important to understand what foods I could eat and what I couldn’t eat and what made spikes and what didn’t ... If I hadn’t tested, I would have been on a really weird diet that was probably more unhealthy” (Harry)*

*“It helps me. Because if I eat something that makes my blood levels too high, then I don’t eat it again! Because before then I’ve been just working blind!” (Alice)*

Some HCPs were described as being more understanding. They did not advise their patients to avoid SMBG; rather, they were neutral about it and accepted the patient’s freedom to choose it. Some participants believed that this attitude was mainly due to economic reasons: they suggested that their HCPs did not officially recommend SMBG to them because the health care system limited prescriptions of it. Accordingly, the participants believed that the HCPs considered SMBG to be a helpful tool for some people with T2D and were not against it:

*“I discussed [SMBG] at one stage and she said I didn't need to, she didn't say don't do it ... I can understand why, there is so many type 2 diabetics, it would cost the NHS a blooming fortune to give funds, because they have to if it's a type 2 diabetic; but it's a tool that is really useful. I don't think they are against it, it is more they don't want to commit, because if they're saying it would be helpful, they would maybe have to prescribe it on the NHS. And I do understand that” (Sarah)*

*“[My HCP] said that we were supposed to tell you not to test, she said: as you are testing it's generally good, carry on doing it ... but then she is Type 1 anyway herself ... I think they must have told you not to test in case they ask to pay for metre, but once you bought your own metre and you are testing, I think they are more than happy that you are doing it, because after all you are doing their job for them, aren't you?” (Elizabeth)*

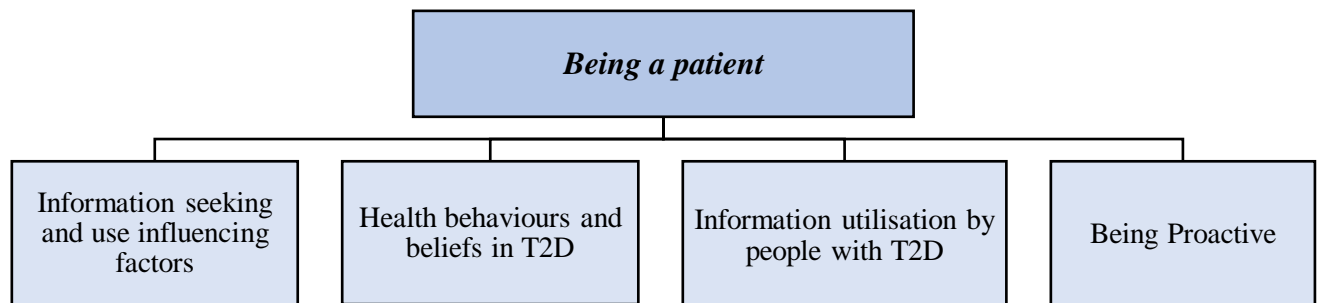
*“I understand the reason behind the NHS guidance, which I respect, is a reasonable chunk around budget because it is expensive” (Harry)*

In conclusion, the knowledge obtained from the OSGs helped the participants become aware of conflicting practical information. Since the information was not supported by the health care system, they were usually not aware of it before using the OSGs. This acquisition of new information did not just fill a knowledge gap, it also enhanced the health literacy of patients, which in turn impacted on how they related with the HCPs. Thus, by improving their health literacy about treatment options, the OSGs made the participants feel more confident in their relationship with their HCPs and helped create a more balanced communication between the participants and their HCPs. This confirms previous findings that the use of online communities contributes to making communication between HCPs and patients more equal (Benetoli et al., 2018; Smailhodzic et al., 2016). However, the findings of this study showed that the use of OSGs introduced the participants to new treatment approaches that might have not been supported by their HCPs. The conflicting information could also lead to tensions between participants and those HCPs who did not support the participant's decisions to follow practices that conflicted with the information recommended by their HCP. It might also have had a negative effect on the trust between patients and their HCPs, as discussed in Section 5.3.2.1.4. The findings indicate that participants had a harmonious relationship with

those HCPs who were supportive of their choice, even if that choice went against NHS guidelines.

### 5.3.2.2 *Being a patient*

This theme investigates health-related behaviours of the participants regarding their T2D. It particularly examines their motivations to perform health actions, behaviour in controlling and managing the condition and beliefs. Figure 5.3 below shows the subthemes of this main theme.

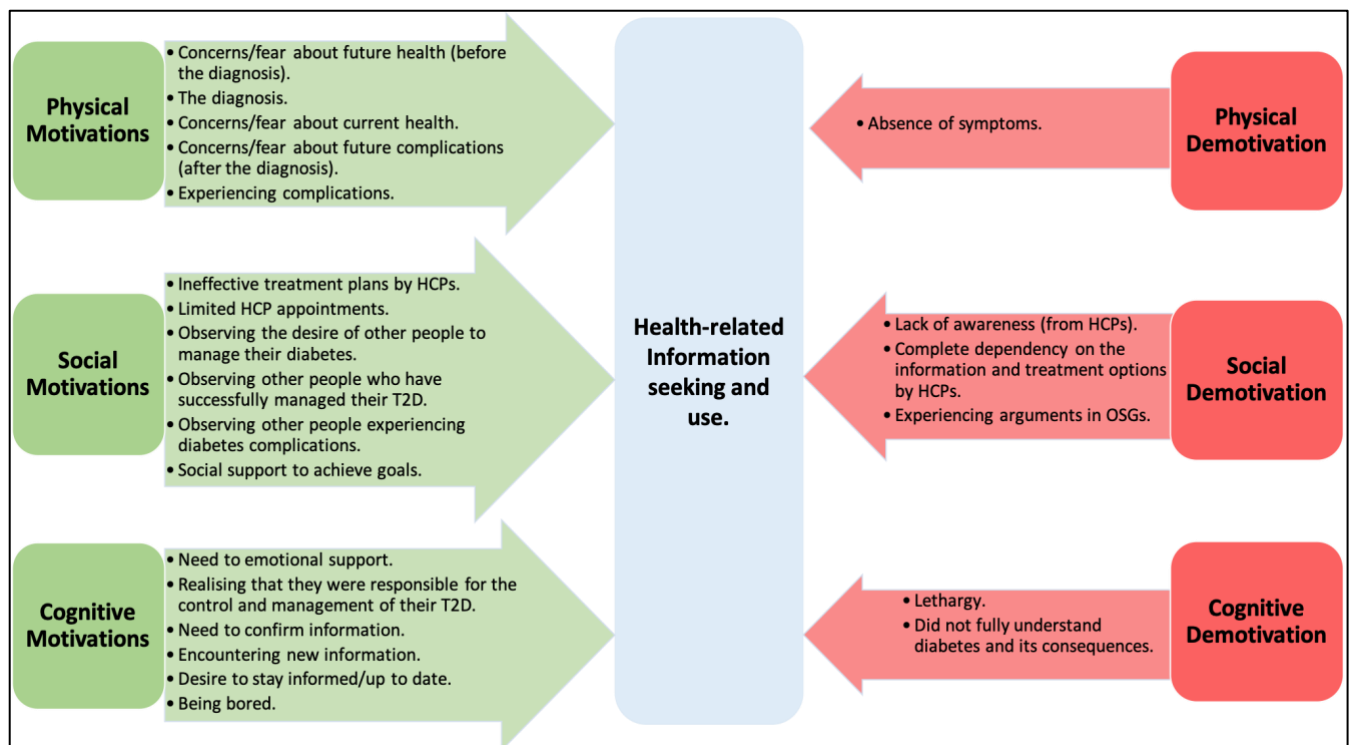


**Figure 5.3 Subthemes of the theme ‘Being a patient’**

These subthemes are presented in detail below.

#### 5.3.2.2.1 *Information seeking and use influencing factors*

The participants explained that they were both motivated and discouraged to seek health information and make actions related to their T2D by a number of factors. This subtheme investigates the factors that influenced their motivations to make a health-related action. The factors can be categorised into three main groups: physical, social and cognitive, as Figure 5.4 shows.



**Figure 5.4 Motivations and hindrances to seeking and using T2D-related information**

As Figure 5.4 shows, for some participants, the fear of having diabetes before the formal diagnosis was the main motivator for them to take action regarding their health. They suspected that they would be at risk of being diagnosed with the condition in the future because of having other contributing health conditions to diabetes. They, therefore, started to look for information and take some actions to reduce their risk of being diagnosed, as the following quote explains:

*“I have a couple of other health issues that contribute [to having T2D] ... I’ve been expecting it for about 20 years to be honest ... I was already on the forum ... a few weeks before I was diagnosed because I thought: ooh no! my glucose tolerance test is coming up! So I found the forum and I actually think that my diagnosis would have been at a higher level if I haven’t already done the forum and doing some of the good things that people suggest on it” (Alice)*

*“I had already started looking before the actual diagnosis confirmation, I started searching upon getting the first HBA1c result rather than waiting for the 2nd one to confirm it” (Lucas)*

This factor was outlined by the Health Belief Model (HBM) as the perceived susceptibility to the illness. As the Model explained, the perceived susceptibility is a subjective perception

that influences individuals to react to the risk of having an illness if they believe that they were susceptible to the condition (Janz & Becker, 1984). Participants' concerns and fears about their future physical health made them seek health information and take actions. Concerns and fear about their current health were also motivators. Several participants explained that they started to seek information and take actions regarding their health when they had negative indications, such as high blood glucose test results, as explained in the following example:

*"It's my review [that made me look for information], all my numbers have gone up again. And I knew they would be up. You just you get this feeling in yourself that things aren't the same as they were. So I thought that trying to take myself in hand and just do something there. Do something positive"*  
(Daisy)

The diagnosis, on the other hand, was the main motivator for several participants. They decided to transform their negative emotions resulting from the diagnosis into positive reactions. They, therefore, sought health information and consequently undertook certain actions, as the following quotes explain:

*"I think it was probably as soon as I got the diagnosis, I was so scared. You know, so I went online. And then I quite quickly found the forum"* (Catherine)

*"[On the day of the diagnosis] I was angry and disappointed more with myself than anything and then afterwards and since really has been more determined to get myself in the best position possible"*  
(Harry)

*"[After the diagnosis] it's kind of Oh sh\*t! Let's do something about it was my main You know, my main reaction"* (James)

Besides the diagnosis, some participants highlighted that the fear of having complications in the future, as a result of having T2D, was their motivator, as explained below:

*"I mean really that has to be two sides of the same coin for me because the fear of having diabetes is the fear of complications"* (Harry)

*"I was on google ... looking at T2D, the world complications came up ... once I read up on it I was horrified ... the more I read the more terrified I got to be hones ... the amputations ... I think it is something like there are 500 or 700 people a day in the UK who are being imputed on. The loss of sight, the kidney problems ... the fact about losing limbs ... that terrified me"* (John)

This was highlighted by the HBM as the perceived severity to the complications of the condition. The model explained that the stronger an individual's perception of the severity of an illness is, the more likely they will take an action to prevent it (Carpenter, 2010; Rosenstock, 1966). The results showed that when the participants sought information about the condition, they encountered information about its possible complications as well. This, as a result, increased their perception of the severity of the complications of T2D and, subsequently, made them determined to control and manage their T2D.

The desire to stay in control of their physical health was a further motivator. Participants explained that they sought and used health-related information to gain control over their health. Accessing the OSGs helped them to achieve this, as well as to become more confident about their T2D control and management, as the following quotes illustrate:

*"I just feel at the moment in touch with that I have reasonable control of my diabetes. So you know, I just limit myself to one or two threads [on the forum]" (Isabelle)*

*"you learn about something and you sort move on and you need change because I'm now somebody you know who's very fit, very thin, very much in control of my bloods, where I wasn't when I started. You become more confident as well, confident" (Sarah)*

Experiencing some of T2D symptoms and complications was another motivator for several participants. When the symptoms were more noticeable, they decided to act to limit its spread, as explained in the following examples:

*"One of the things that made me desperate to find a solution was some of the diabetic symptoms was starting to be more prominent ... became more prevalent ... that pushed me to point to try and do something about it whereas years earlier symptoms were not quite so obvious. ... the symptoms drove me to try and find a solution" (Andrew)*

*"I was getting concerned about myself that summer and because my weight was coming back on and you know I just saw the future and then I started to read" (Sarah)*

*"The reason I went to the doctor was I woke up one night with this weird kind of all over the body in the needle. So kind of like general neuropathy all over my body, which kind of frightened" (James)*



For other participants, the ineffective treatment options advised by their HCPs motivated them to look for alternatives. They believed that the prescribed treatment options would not improve their physical health. Their desire to control and manage diabetes, therefore, led them to seek information and make health-related actions, as illustrated in the quote below:

*“To be fair, I was already eating the Eatwell Plate, so there is no point in me in doing that. I got being diabetic for eating that. So, I went searching and I found [an OSG], and from there, I lost 5 stones, put my diabetes into remission, and never felt better” (Mary)*

Similarly, the suggested treatment plan by HCPs made another participant who had started seeking information before the diagnosis more determined to find alternatives to what he was provided by his HCPs, as explained in the following quote:

*“I was given some booklets said I should continue with the low fat mainly carb diet that was causing my blood glucose to spike, and was a probable cause of both my Angina and my diabetes” (Lucas)*

For other participants, limited appointments with HCPs made them take responsibility for themselves. Therefore, they started to seek information and look for treatment options, as explained in the following quote:

*“When you’re not pregnant, you don’t get any very regular appointment with the doctor or anything, so I think it was in the years following that, I think I looked it up online” (Sally)*

Additionally, social surroundings were another motivation to start seeking information about the condition. For example, one of the participants explained that the main motivator for him to take action regarding his physical health was seeing his friend worried about diabetes more than cancer, as the following quote shows:

*“About three years ago, a comment made by my best friend shocked me and that basically started me off on the research, because he was suffering from cancer, stage four, and he was also a diabetic. I was so concerned about his cancer and I was telling him to take care, and he made the remark that*

*his diabetes was going to kill him before cancer. And that started me off on my research ... Just to get as much knowledge as I can, to sort of try to treat it in some manner” (Oscar)*

Comparing their experience to other OSGs members who successfully controlled and managed the condition motivated some participants to take steps that would improve their physical health, as the following quotes show:

*“[After reading the success stories] you suddenly started saying oh yeah this is actually do-able and let’s do it! Let’s try it! If whole lot of people could do it and they have kind of success, why I couldn’t do it! [Knowing that] was really powerful” (James)*

*“[Reading about the success of other members] gave me the sense that there are other people that were successfully managing it. It wasn’t the slippery slope down to amputations. Practical advice on how actually to do it” (Sophia)*

Seeing other people experiencing diabetes complications was also a motivator for some participants. It kept them focused on their health and encouraged them to control and manage their T2D by continuing accessing and using diabetes-related information, as the following quote shows:

*“[My friend] got severe retinopathy, she’s got severe peripheral neuropathy she was admitted to hospital ... with the prospect of possibly having one of her feet amputated. They think they may be able to save the foot, but they’re not sure ... I don’t want to be like her” (Emily)*

Social support also contributed to motivate participants to focus on maintaining blood glucose levels and achieving their goals. The support could be from their family, friends and HCPs, as explained in the following example:

*“I moved from the [a city] to [another] so they were change in the GP ... [the new GP] understood the low carb message, and how to deal with it, and you know when I was talking to him, I understood completely what he was saying and he understood what I was doing and that helped me as well” (Andrew)*

*“My partner is becoming even more than I am ... [my partner tells me] no you can’t have that rose berry ... [my partner] is very good at keeping me in control” (James)*

Social support could also be obtained from other OSG peers. Many participants highlighted that they kept accessing the OSG to obtain emotional information. Even when they achieved a stable level of diabetes management and control, they kept using the OSGs to help them maintain their focus, as the following quotes show:

*“[Using the OSG] gives me friendship and support but also accountability. Keeps me on course. It encourages me to keep going” (Sarah)*

*“I find [posting in the OSG] keeps me accountable every morning, announcing your fasting blood sugars to a group of people” (Jessica)*

Cognitive factors were also equally important motivators. Several participants explained that, when they realised that they were in charge of their condition, they became active in the control and management of their T2D. Understanding this was a turning point for many of them, as the following quote explains:

*“It’s one’s mental state one’s attitude towards [T2D]. I think it’s all dependent on the individuals. I think All those people down the all these forums, usually, I would imagine they will be successful in whatever they do because if they are making the effort to find out as much as they can and taking the trouble to read going on diets etc. If they have the willpower, I would imagine the majority will succeed. Because the information is there, the treatment is there. Just need the willpower and the sacrifices to go with it” (Oscar)*

*“It’s up to you. It’s your diabetes. You have to manage it. So [HCPs provide] help as much as I want. But it’s ... more on the patient” (Daisy)*

This confirms the findings of the previous Chapter, that reaching the awareness that it was not enough to take medications and follow the instruction provided by the HCPs was a main motivation for many OSG members (as explained in Section 4.3.2.2.1).

Information confirmation was another factor that led many participants to seek information about the condition for the purpose of examining information. They then either used the information or rejected it:

*“I mean, I don’t believe everything I read online ... I kind of research myself when I read something, and I put up a web page, and I just check it out” (Jessica)*

*“I do look at what the different ‘factions’ of current research are saying, look at the robustness of their studies and make up my own mind” (Lucas)*

Encountering new information was another motivator for few participants. They had other motivations to start searching information about T2D and when they did, they discovered new information about how T2D can be managed. They then started using the new information to improve their physical health, as explained below:

*“Up to the 21 months’ time from diagnosis ... I just went along with the standard advice but then I discovered the forum and it was then that things started to change” (Sarah)*

*“Once I got onto the forum I just said I am interested! I’m curious! The progress I’m making was poor ... the forum gave me lots of interesting information; no one is telling you what to do just telling me what they have done” (John)*

For other participants, the ambition to keep updated about current diabetes research and how other people were managing it was the motivation to keep seeking information. This motivation was usually mentioned when they already reached an advanced management stage. At this stage, they were able to control and manage their condition and were satisfied with their treatment plan. They kept obtaining information about the condition because they had the desire to stay informed about developments in diabetes, as explained in the quotes below:

*“I go on [the OSG] a couple of times a week, maybe just to catch up on new stuff... I go in there just to see what’s new or to look for something specific ... I’m more likely to go and read what other people are doing or read links to new research findings” (Emily)*

*“I’m particularly interested in research based posts ... research about people reversing or putting diabetes into remission and things about the science of it ... if I see a post that’s about research with anything to do with diabetes I tend to read it and maybe watch the videos of the presenter from the conference or I’ll read the academic material” (Sarah)*

Other members explained that, when they retired, they had more time. They, therefore, engaged in the OSG and spent more time in it because they felt bored, as the following quotes show:

*“I have to admit, I think it’s purely boredom that makes me go into all these forums, having so much time on my hands, with nothing else to do” (Oscar)*

*“I was just kind of retired from work so it was, it was kind gave me a new hobby it was kind of looking at diet and T2D and nutrition ... something that I would never been really interested in” (James)*

As the examples show, being retired and feeling bored was one of the main motivations for various participants to keep seeking information on the OSGs.

In contrast, a number of factors contributed to demotivate participants from seeking information about T2D and to take action. These factors can be mainly divided into three main categories: physical, cognitive and social, as shown in Figure 5.4. The absence of physical symptoms made many participants feel that they were not susceptible to diabetes. It reduced the seriousness of the condition and its complications, as illustrated in the quote below:

*“The whole problem with diabetes is there is no symptoms. You know, there’s virtually nothing that you’d be aware of that your blood sugars are running high” (Harry)*

*“[Seeing the symptoms] pushed me to point to try and do something about it whereas years earlier symptoms were not quite so obvious” (Andrew)*

*“I’ve been quite large for quite a long time ... it’s slowly been getting fatter and fatter and fatter over the years. So I kind of thought this pointlessness, [losing weight] is not going to happen. [Obesity] didn’t really have an impact on my health. So I was asymptomatic until [I got diagnosed]” (James)*

The second factor to demotivate participants from seeking information about T2D and performing actions was linked to cognitive factors. A number of participants explained that lethargy was a factor that demotivated them from using information they were aware of, as the example below shows:

*“Exercising is very important generally for everything. You know, I’ve always known that I think everyone knows that but you know, knowing and getting your ass off is another thing altogether”  
(Oscar)*

Several participants explained that they had been inactive regarding their T2D in the past, because they did not fully understand the condition and its possible complications. Some of them were in the pre-diabetes range and did not make any action about it because of absence of information:

*“I didn’t [do much about my T2D years ago], I was too busy, I didn’t fully understand the implications. I was trying a little bit, I thought I was on the right track with just cutting out the added sugar and stuff like that” (Andrew)*

*“I didn’t know a lot about it ... and since actually going back and looking at my records, I discovered that in 2004 I had a pre diabetic HbA1c ... I mean, if I had known how dangerous it was then, if I had known in January 2014 what I knew in October 2015. I would have done a lot more about it probably, and I would have saved myself a lot of” (James)*

*“when your overweight and things and I was on the point of obese, nobody said to me oh come on, look at this, how can we change it” (Sarah)*

This is also linked to a social factor, such as the support provided by the HCPs. For instance, in the previous example, when James was in the pre-diabetes stage, he was not provided with appropriate information on the risk of T2D and practical information on how to prevent it, as the following quote shows:

*“[When I got the pre-diabetes diagnosis on the phone with not information,] no one really explained what it was or how dangerous it was ... [the pre-diabetes diagnosis] wasn’t really made much off by the [HCP] ... they kind of found out that all your HbA1c is 44, it’s kind of more it’s kind of pre diabetic, you need to lose some weight. I said Okay!” (James)*

Complete dependency on the information and treatment options by HCPs was also described as demotivating for various participants. It led them to be less active and made them rely on the information and treatment options provided by HCPs only, as described in the following quotes:

*“I accepted everything that the medical profession said that they were the best they were the correct and they are the right person, I put my life in your hands” (Oscar)*

*“Up to the 21 months’ time from diagnosis ... I just went along with the standard advice [from HCPs]” (Sarah)*

*“I wouldn’t say before I was managing [my T2D]. I was taking the tablets and taking the doses of insulin I was being given. I wasn’t changing anything. I was just told to take this and It will be all right; like that sort of thing” (Jessica)*

Another factor that contributed to demotivating some participants and kept them from seeking information from OSGs was encountering negative issues, such as arguments, in the OSGs. As Section 5.3.2.3.2 explained, the participants experienced a number of negative issues while obtaining information from the OSGs. This led a number of them to be reluctant and less interested in keeping on with seeking information from the OSGs, as the following quotes show:

*“I am probably not going to last very long in the forum. I find the rules a little oppressive and the moderators heavy-handed. They are concerned about not offending delicate sensibilities. ... it really depends upon whether I can come to an agreement about where the lines are about behaviour”*  
(Lucas)

*“administration on the forum got a very sort of anti that, wants to challenge it, other members came in and the bullying was .... It didn’t bother me so much in that sense, because I’m reasonably tough, but other members were just sort of put off. Other members suddenly wouldn’t post and then ...this is why I don’t contribute here anymore” (Isabelle)*

As described above, participants had a number of factors that motivated or demotivated them from seeking and using health information and, as a result, improve their health. The findings showed that the earlier the participants started obtaining information about T2D, the better they reacted to, and coped with, the diagnosis and how they controlled and managed the condition afterwards. This has also been highlighted by other studies that reported the time of information seeking played an important role in how the condition impacted patients (Ankem, 2006; Mills & Davidson, 2002; Wong et al., 2000).

The diagnosis was one of the key motivators for the participants to start seeking information regarding their T2D (Clark, 2005; Jean, 2017; Morgan & Trauth, 2013; Newton et al., 2015). Most of the participants explained that being diagnosed with the condition would encourage them to search for diabetes-related information. The diagnosis might have also raised negative emotions, such as anxiety, anger and uncertainty which, as a result, increased the need to seek diabetes-related information (Clark, 2005; Newton et al., 2015). The findings also suggest that the desire to be confident in the control of their physical health motivated many participants to seek and use health-related information. Patients tend to seek and use health-related information for the purpose of staying in control of their health conditions (Jean, 2017; Wong et al., 2000). OSGs helped members to seek and use diabetes-related information even when they were already in control. Being part of the online community encouraged many participants to keep seeking and using information from the OSGs. They continued using the OSGs to stay motivated, informed and entertained.

#### ***5.3.2.2.2 Health behaviours and beliefs in T2D***

This subtheme captures how the participants acted to attain, maintain and regain good health. It also highlights their perceptions and beliefs about controlling and managing T2D.

Most participants reported that self-monitoring of blood glucose (SMBG) was an essential tool for them to measure their progress and achieve their goals. The majority of participants explained that they learned about SMBG and its importance from their peers in the OSGs. They explained that SMBG assisted them in knowing how their bodies reacted to food, medications and physical activities. They believed that SMBG played a key role in knowing how their bodies reacted to these factors, as explained in the following examples:



*“Testing foods/ meals with a BG meter because different people have a different reaction to certain food e.g. some can even eat a banana without spiking their BG, others like me can’t even eat a raw carrot. Some can eat as much protein as they like while others have to limit it” (Lucas)*

*“Because before then [SMBG] I’ve been just working blind! like you know if somebody says carbs will raise your blood glucose, you’ve got no idea how much! Or how long for? Or what portion size you can tolerate? anything like that without a test meter” (Alice)*

*“But my fingerprint testing average for meals I am eating it doesn’t go above six, six and a bit. Whereas if I have you know, I did I did try a portion of white rice with a curry and I was in the 8 which I haven’t seen any other meal I am eating” (Harry)*

SMBG helped them particularly when they introduced a change into their daily lifestyle, such as following a low carbohydrate diet. The method helped them discover the right amount of carbohydrates that suited them, as explained in the following examples:

*“I was testing every morning, before and after meals. I was testing specific foods to see which ones I had more of an issue with even though they were in my carbs limit. So, I found 100 grams a day and no more than 30 in one particular meal [is perfect for me]. I’d get no spikes at all” (Emily)*

*“[I] have to test at all meals to know what you are doing. To me before the meal and then 2 hours after your meal and what you’ve eaten should not raise your blood sugars, so I know what I’m eating” (Mary)*

SMBG helped also in motivating the participants to achieve their goals. By seeing improvements overtime through SMBG, people kept on track to achieve their final goal and adapt and maintain a healthier life habit, as explained in the quote below:

*“Because I’ve been testing and because I’ve been making changes and sticking to them I can see the numbers changing and it’s a positive that you are motivated to carry on” (Harry)*

SMBG was a key management tool especially when deciding to make a lifestyle change. However, when people reached a stable status it became less important. At this point, they were more confident about how different factors (e.g. food, physical activities, medications) impacted their T2D and they were successfully able to balance them and maintain a good level of health. SMBG, as a result, became less frequent when they achieved this status, as the following quote explains:

*“I don’t do blood testing so often now, because I know what I can eat, I’ve been doing it long enough, but if it’s something that I haven’t had before, then I’ll still do it occasionally, just random just to make sure nothing is gonna rise” (Mary)*

Reaching and maintaining this stable status was challenging for several participants. They explained that balancing the different factors influencing T2D management and control was exhausting and took a lot of effort. They managed to get over this struggle through talking to their peers, as the following quote shows:

*“For myself, I need to take my medications on time in appropriate way and balance it with my meals and exercise and whatever else is going in my life. Which is very, very difficult and is a constant struggle ... talking to other people and getting their advice [and] working to my meter [helped me to balance them]” (Sally)*

The majority of participants mentioned that changing their diet was key to improving their health status and maintaining it. They explained that, after making changes to their diet, they were able to balance the different factors and stay stable. The participants outlined that the use of OSGs and information exchange between members assisted them in learning more about how and what include in their diet. Dietary control helped them to manage their T2D, even when other factors were absent (such as not being able to exercise regularly). It also helped them reduce medications, control and manage their diabetes without medications and/or lose weight. Most participants referred to reducing carbohydrate intakes when they mentioned effective diet changes, as the following examples explain:

*“I had difficulty with [exercise] because of my lifestyle. My lifestyle was a lot more sedentary. It has been a lot more sedentary because you know where my job ... [my HCP] did advice exercise; in fact, I got a free pass for 3 months to the gym; but getting there was difficult ... but what did work was the change of diet and that was the magic, that was the key to me and many and that was the solution to many other so that was just a radical change of diet by cutting out carbohydrates.” (Andrew)*

*“I’ve just changed all of my diet significantly; lost quite a lot of weight but just been following a healthy diet and cutting out all refined carbs ... I can stop taking medication and manage it with just diet” (Harry)*

*“[I believe] if you don’t eat carbohydrates your blood sugar goes down to normal and you don’t have to worry about [diabetes] anymore ... my blood sugar has gone right down to normal ... it’s difficult*

*here [to exercise because] it is a small village ... [it] is not a possibility ... that doesn't make much difference [because diet control is effective by itself]" (Elizabeth)*

Attaining this stable status was challenging for many participants. For example, a number of them explained that they followed other approaches for a period of time, but they were less effective. This was typically reported when they followed the official treatment guidelines (see Section 5.3.2.1.5). They explained that before reaching a stable status they were caught in a vicious circle of diabetes symptoms that they could not manage, as the following quotes demonstrate:

*"I had taken the doctor's advice in half of the six weeks ... I hated it ... the progress I'm making was poor and actually gone to the doctor with a 56 HbA1c. six weeks of being starving, miserable hungry all of the downsides of diabetes ... I was just hungry all the time, hungry and starving myself, and I wasn't really losing weight a lot and I wasn't getting better" (John)*

*"It [referring to the previous treatment approach] was not working, because I could see that my fingers won't be working, I could see my weight was going back up, and I was sttttarving! and I was exercising like fury and it wasn't working!" (Sarah)*

Medications were another factor influencing how the participants controlled and managed their condition. They had different beliefs about the role of medications in treating T2D. Some of them believed that medications should be the last option in managing their T2D. They challenged their HCPs when they advised them to take medications and tried alternative methods to control the condition, as they believed that medications would worsen their health, as explained in the examples below:

*"I've already seen what [medications] have done. I had a friend who lost his job because of the side effects of statins. And then the Metformin, I am a bit phobic about medication. I just don't like to take it if I possibly can. So I didn't. I had quite a battle with the doctors to start with, but I didn't take any medication from day one really" (Catherine)*

*"My understanding is that Metformin tends to be the first step on a road of increasing drugs and complications. My mother was on Metformin and had peripheral neuropathy and retinopathy... and as they increased her Metformin, she had the most horrible diarrhoea and the spinal stenosis got worse, she'd have accidents all over the house, so distressing to watch" (Emily)*

They explained that it was not easy for them not to follow the advice of their HCPs regarding taking medications to control their diabetes. However, the peer support obtained from the OSGs assured them that would not impact negatively on their health. This, therefore, made them confident in their decision, as the following quote shows:

*“It’s, it’s really, really scary, going against your doctor or going against the general opinions [regarding not taking medications], you know, making a stand against that is frightening and sometimes you start to doubt yourself. So probably without forum, um, I would say I would have had a very different way of doing it” (Catherine)*

Other people were not able to go against the advice from their HCP nor did they try other treatments options. This was mainly because they were not interested in making changes to their lifestyle, and they believed that the treatment options provided by their HCPs were the best for them or had limited health literacy in diabetes management and control alternatives. These people, therefore, were struggling with the control and management of their condition and were dependent on medications for a long time, as explained in the quotes below:

*“I think there are people who don’t want to change what they eat, what they drink because partly they have told that they should take the pills and get on with it so again ... that’s because they don’t wanna change and ... I guess there are some people that are happy to do what the doctors tell them” (James)*

*“Some people if they wouldn’t understand it or have the ability to think about nutrition in that way. I think some people just want to be able to take a tablet and eat what they like. But unfortunately, I know that those are the people were progressive, and then they want to insulin and so on” (Catherine)*

Some participants who changed their health habits to manage the condition explained that it was not an easy process to adapt to the new habit. For example, when they shifted from one diet plan to another, they explained that they had relapses and could not easily adapt to the new change:

*“I’m trying the low carb as best as I can ... [I] tried it when I was first diagnosed and fell off the wagon, buried my head in the sand, as people do ... [however] this time I’m serious ” (Daisy)*

*“The first time you go with it; you just feel I can’t do this for the rest of my life ... You know there are times when it just seems too much to carry on turning things down and not eating things ... a number of people would say: oh, you lose your sweet tooth over it after a while ... and I pop in and say Actually, no, I haven’t; it is still there ... I’ve never lost my sweet tooth. I’ve never stopped wanting those foods even after 16 months. So, I think it’s wrong to tell” (Emily)*

On the other hand, other participants were more dogmatic and believed that people with diabetes should be more determined to adhere to what makes them healthier and should not relapse to unhealthy habits:

*“I’m a bit autistic in [making changes] ... I tend to look at things in a straightforward logical way ... There are lots of threads in the forum that the emotional well-being and [OSG members posted:] I am frustrated [because] I already ate a slice of bread and [I think] it’s like most fuc\*ing stupid ... I don’t get involved in those threads because I have so little empathy with people experiencing that, I just can’t, it doesn’t come in my head that why would you do that [when it is bad for your health]?” (James)*

Being motivated to make changes to their lifestyle to healthier habits was key to several participants. They illustrated that their motivation was the main drive to continue with the new habit. Their positive blood test results reinforced this motivation and helped them to keep doing the new habit:

*“It is really hard to give advice on how to do it because really without the motivation, the willpower to do it people just will not ... I’ve been making changes and sticking to them I can see the numbers changing and it’s a positive that you are motivated to carry on” (Harry)*

*“For me [the driver] was the mission over this ... I had to get out of this mess I got myself into ... really just want to bring about some change in my medical status ... and once my results started come in and they proved in even more you know even stronger kind of motivator I guess” (James)*

Most participants believed that people with T2D were the key players in the control and management of diabetes. They were the ones who dealt with the condition on a daily basis and, therefore, their choices and preferences should be respected. The participants thought that they should be in a position of equality with their care providers (as Section 4.3.2.2.2 also reported). In such a relationship, both the patient and care provider contribute equally to

the treatment plan. They also highlighted the importance of providing the patient with information about various treatment approaches, as explained in the following quotes:

*“There is a need to be more patient ownership ... involving the patient, and not making assumptions ... you’ve only got ten minutes, you kind of have to motivate a patient” (Sarah)*

*“I would say the best option would be to give us a choice. Let’s know the Eat Well there, but there are the other options ... one size-fits-all this what [HCPs] do, does it work? No, but this is what you do!!” (John)*

*“I think [diabetes] should be managed with more information given to the patient and more choice; not just here take some drugs and come back for some tests in a year. I think involving patients in their own treatment and allowing them responsibility; obviously not everybody’s going to respond to that! But at the moment we’re not even given the choice!” (Alice)*

They explained that personal differences between individuals should be recognised by health care providers and that patients needed to have information about alternatives. The reaction of individuals to different factors (e.g. medications, diet plans, physical activities) and their preferences about treatment plans must be considered to support them attain and maintain better health. They highlighted that some people might not be able to follow and maintain a certain management approach and, therefore, personal differences and response to treatment options needed to be considered:

*“Every case is different even some people affected by sweetness and other artificial sweeteners and some other people are affected by some fruit but not others. Here is the case that every condition, of every individual, is basically different” (Andrew)*

*“From my personal experiences [the best way to control T2D is] by Diet. I think that’s the most powerful way but I also acknowledge that that’s not always going to be everybody’s choices. You know, for some people, they would rather flop back out and try and do it all by exercise ... I think medications got a place for some people, particularly depending on what else may be wrong with them what their lifestyle is. But then it’s all about doing making the choices, knowing the benefits and the disadvantages of that method” (Sophia)*

*“[If] you’re quite happy with your medication with what whatever lifestyle you’re having, then continue with it ... I think it’s all dependent on the individuals” (Oscar)*

*“My nurse said to me: well go to the gym. I’m 72!!! You trying to kill me off! And you can’t exercise your way out of a bad diet, I just walk now” (Mary)*

*“I think [T2D] should be managed ... by diet. But not everyone can cope with that ... not everyone can get all the resources they need or understand about cooking and nutrition. And not everybody can, you know, understand the information ... but some people will need medication, for whatever [reason]” (Catherine)*

In summary, this subtheme provided insights into how the participants' strategies to regain good health, and their beliefs in the control and management of the condition. Throughout their journey, participants found that diet control was the optimal and most effective approach to manage their condition. The information and support obtained from the OSGs helped them to discover the wide range of food options that they could consume to stay in good health. Understanding the importance of dietary habits for people with diabetes and the effect of a sedentary lifestyle were reported to play a critical role in improving diabetes control (Sami et al., 2017). The use of SMBG tools, on the other hand, assisted them in knowing how their bodies reacted to different factors and navigated them to discover the best approach for them. Even after knowing the best approach, they explained that it was challenging for them to maintain such approach and adopt new habits. Relapses to unhealthy habits, such as eating unhealthy food, occurred many times for many participants. This might be linked to tiredness (Chaput, 2010), stress (Torres & Nowson, 2007) or negative emotional effects (Bekker et al., 2004). However, their motivation to attain their goals helped them to get back on track again. The use of OSGs reinforced and enhanced this motivation (as explained in Section 5.3.2.3.1). The use of OSG also encouraged them to try other treatment options and assisted them to be independent from using medications to control and manage the condition. The participants' journeys to regain good health and maintain it gradually established different beliefs about the most appropriate way of treating T2D. They believed that HCPs should acknowledge personal differences between different patients. Patients, therefore, should be informed about different treatment options and they also should be involved in designing treatment plans. They felt strongly that ownership of the control and management of the condition belonged to the patients, to achieve better health outcomes.

### ***5.3.2.2.3 Information utilisation by people with T2D***

Participants varied in how they utilised the information they obtained from the OSGs and other sources and turned them first into actions and then habits. While Section 5.3.2.1.4 examined how participants evaluated the information they obtained from OSGs, this sub-theme investigates how they rationalised and utilised this information.

Participants explained that the *type of information* they obtained and *how applying it would affect their health* played a major role in utilising the information. For example, information about diet options was less critical than information about medications. They, therefore, made more efforts in utilising information about medications:

*“If it’s something simple, then you just give it a try and see how it happened. You know, try replacing this with this foodwise, that’s a very simple thing to put into practice” (Sophia)*

When participants were exploring the information exchanged in the OSGs, they became interested in applying some of the information. Their interest made them curious to seek more information before using it and turning it into an action:

*“I was trying to find out more about the liver in relation to blood glucose. So I asked some questions [on the OSG] and then I have to ask some more questions to try and get to work trying to understand it and then from there, I think I also maybe just googled in general ... I would probably just Google in general and follow any sort of links that people offer as well” (Catherine)*

*“[reading the forum made me interested in buying an SMBG equipment] ... then I thought I should find out: well was it worth me investing because it’s more than strips, and so I had serious decision to make; what were people saying was accurate? Inaccurate? how hard was it to insert? and what benefits have people had from it? and I found that all out on the forum” (Sarah)*

They explained that the application of information from the OSG might create further informational needs. These needs were further questions related to the applied information:

*“And then I committed buying it and then I asked for help with the practical day-to-day” (Sarah)*



*“If it works then I don’t need to feedback anything. If there is some form of complications, then I might ask again: what happens if I find this. I would feedback if I had a problem and somebody will try and address that problem with their experience” (Sally)*

Most participants explained that when they were convinced that applying a certain health action would benefit them, they would apply it progressively. When they applied the information that they sought from the OSGs, they monitored how their bodies reacted to the changes and assessed it:

*“If it resonates with me yes, and I will try and do it sensibly, like I will just my blood glucose when I’m doing whatever it is and I will take note of what’s happening, and I won’t just you know adopt some wacky diet. I’ve got to research it and then I go do it” (Alice)*

*“I started with bits and pieces ... I did not dive straight, and since then everything was working out ... I did that for a week or two, how did I feel, my scores came down. so it was like that works for me so I carry on doing it” (John)*

*“I started it gradually, I believed what they’ve written about not having bread and potatoes” (Mary)*

The application of the information obtained from the OSGs helped participants to judge whether the information was useful for them or not. If the information confirmed its usefulness, they would continue using it. For example, there was an approach that OSG members exchanged about cooking then cooling carbohydrates. This method was reported by some members to have fewer negative consequences for their blood sugar levels. Some participants read about this approach and tried it and they varied on how it impacted them, as the following quotes show:

*“Like the trick with cooking pasta then letting it go cold then reheating it. I mean that doesn’t affect your blood glucose. [While] if you cook pasta and eat it straight away then it will change your blood glucose sky high; if you cook it let it go cold and reheat it doesn’t because the form of starch changes from a soluble to insoluble starch ... [it works with me]” (Elizabeth)*

*“There’s this idea that about resistant starch ... It’s an idea that if you cook pasta and let it go cold and then reheated again and eat it then it will not affect your blood glucose as much as if you had eaten uncooked and it’s supposed to be some sort of chemical reaction that happens in the starch when it cools and reheat but affect your blood glucose less ... So, I tried it. It was a complete waste of time for me, it didn’t make any difference whether it was cooked once, twice, or a half a dozen times” (Alice)*

This shows that participants tried some of the information exchanged on the OSGs to judge whether it was beneficial for them or not. It also shows that the information obtained worked for some people and not for others.

After the participants reached a state in which they became confident in the action they had taken and the information they had obtained, they became information providers themselves and shared their experience with other OSG members. They provided other members with information from their experiences and answered questions:

*“If people turned up and they’ve got a question that I used to have then I can help them and it’s a sort of gentle spread of information” (Alice)*

*“It’s kind of turned around now because I find myself being the person that can [give] ... new people ... the basic information, the sort of stuff that I was desperately looking for when I joined” (Sophia)*

*“I feel I should give back as I took as I got so much benefit from it, kind of quite keen to contribute as much as I can” (James)*

In summary, this subtheme examined how the participants utilised the information they obtained and turned them into actions. The type and seriousness of the information affected how they applied it. The participants described that they would usually obtain information about the intended action before, and directly after, applying it. The purpose was to understand and evaluate the action before applying it and to fulfil informational needs that arose from applying it. This confirms the finding of the previous study (Section 4.4.3). The participants reported that they mostly obtained informational support in the *preparation* and *action* stages of behaviour change. Information was mostly needed in the first stage to help them fully understand the action before undertaking it. Applying it usually arose further informational needs about the action taken. The application of new information was mostly accompanied by continuous monitoring of blood glucose levels to assess and evaluate the

change. Participants would accept the new action if its application had a positive effect on their health. Many of them would then turn to be information givers and shared their experiences with other members. They felt responsible to contribute with their new knowledge to the community they learned from.

#### **5.3.2.2.4 Being Proactive**

As the previous subtheme highlighted, some participants turned to be information providers when they had acquired knowledge about the condition or about an action they had performed. Participants explained that, when they achieved a level of expertise with the condition and its treatment options, they engaged in activities that aimed to change the information and care provided to people with T2D. Their goal was to share their successful experience with a wider audience and possibly change the official guidelines.

Participants explained that their experience with the condition allowed them to support others in their social surroundings:

*“There are few people in my village who I’ve helped as well, people come up to me and said: you’re diabetic, [I replied] yes? [they said] well, I’ve just been diagnosed, and they said you can help me. I don’t mind helping anybody” (Mary)*

*“My parents’ neighbour ... was in real shock when she was diagnosed with T2D ... I suggested she reads a couple of books and I gave her the forum link and I didn’t hear anything back for about 3 or 4 months. [I met her then, she] was looking fantastic and she said how grateful she was! I was delighted by that ... she switched to low carb and the weight felt off and she feels really well” (Alice)*

*“One of my customers told me he’s T2D, I tried to help him, tried to talk to him about where I was ... He is four years down the road on medication and he doesn’t have any underline illnesses. I am ten months and I got back to normal. He was me ten years back, five years back, four years back; doctors told me you need to take a medication I probably took it” (John)*

However, when they shared their experience with other people, not everyone accepted it.

Some people had different opinions or lacked determination to follow their approach:

*“One of my friends ... has T2D with severe complications ... So, I was trying to convince her ... I had to be so careful about talking about my low carb diet and my blood sugars when I was there because she'd get defensive, and then irritable and then a little nasty, and this is something you have with people who've made a different choice about this, but feel guilty because their choice doesn't work for them” (Emily)*

*“One woman I had known for a long time, she was diabetic way beyond before me. She's just lost her toes, Oh dear, probably if someone gave you a proper advice you wouldn't have lost your toes because I sent her a message on Facebook said: if you need any help I can help you but she never came back” (Mary)*

Some participants explained that they attempted to change the information provided by their local clinics to other people with T2D. They shared their personal experience with their HCPs and informed them how they were finally able to successfully control and manage their T2D. Many of them explained that their care providers showed no interest to know their experience or transfer it to other people with T2D so they could benefit from it:

*“[My HCPs] never asked me how [I managed to control my T2D after I was struggling for years]!! Like they don't want to know. I've got one [appointment] coming up soon and I'm actually going to be much more proactive, I have decided this time that I'm taking materials in with me to the appointment to help educate them ... I could use some of [the appointment's time] to inform her how I've got it. You know they may be interested, how I got to this stage!” (Sarah)*

*“I have tried [to discuss my improvement with them] and been told that they knew best and no they weren't interested ... I'm not even diabetic because my readings were too low to be classed as diabetic. So having being diabetic a few years ago, something has changed but now I'm not diabetic and they are not interested in seeing me or discussing what I've done to make the improvements” (Alice)*

*“I spoke to a different GP in the same surgery and he wasn't even interested, I spoke to him about diet and he wasn't interested in talking about it” (Andrew)*

*“I wanted to offer to do something at the surgery for them ... when I [gave them] the [information] the first time, they didn't read it and then they handed it back” (Emily)*

*“[I shared my journey with] the diabetic nurse at the surgery and she said ... 'interesting', Yeah? that was her reaction: that was it: just 'interesting' and you think, why didn't you ask me more about it?” (Mary)*

Other participants explained that they joined activities offered by the health care system that aimed to engage patients. They mainly joined Patients Participation Groups (PPGs) that General Practitioner (GP) clinics were required to have to represent the voice of the clinic's

patients (The Patients Association, 2015). The participants explained that they particularly joined the PPGs to change the information and care provided to people with T2D. They requested more information choices and support to be provided to people with the condition:

*“I’m quite involved with our local surgery and the PPG to try and get the get the information about T2D amended it to slightly more modern thought rather than the rubbish they get out, that they gave out the general GP” (James)*

*“I’ve just joined the PPG ... somebody mentioned to me about the potential for peer support group for chronic illnesses, and I’m trying to find out and get that sorted. Because I don’t think the advice being given is adequate ... or the support being given is adequate, choices being given are adequate ... I also applied to join the Public Health Collaboration with the aim of going and educating the health professional. I’m trying to be proactive” (Sophia)*

*“There is a couple of people on the forum that are now on PPGs of the surgeries, I mean we are getting out there, we are telling people about it” (Mary)*

They believed that the current care and information available were not effective. Participants explained that the limited information and choices provided by HCPs exacerbated the problem for many people and contributed to creating serious consequences. This can be prevented by providing a variety of information and support:

*“I think the information has been given to people is making them sicker rather than healthier. I think it’s almost criminal, the lack of knowledge, and that lack of choice, and awareness people are being given. I think the NHS are spending millions of pounds, treating the consequences of diabetes, so they don’t need to be if they were to intervene much, much earlier” (Sophia)*

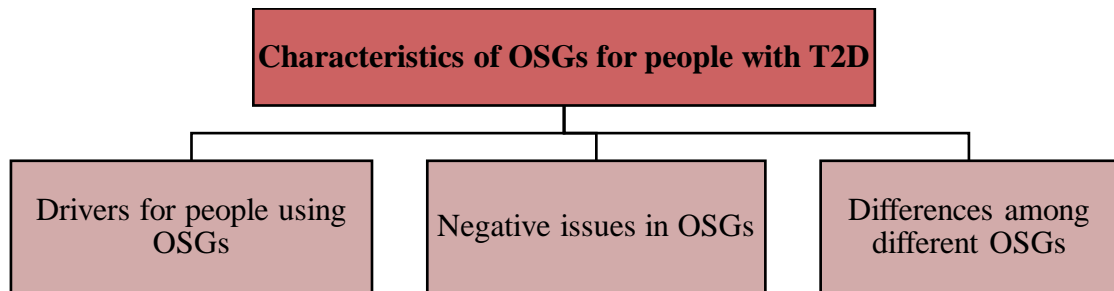
Other participants shared with their peers their experience of how they challenged their HCP’s decisions and sought their rights. For example, when they were not prescribed the SMBG meter and strips, they wrote to their Clinical Commissioning Group (CCGs) to challenge this decision. When they were granted the equipment, they shared the procedure, including letters they sent, to encourage other members to ask for their legal rights:

*“I wrote to the CCG and I challenged them ... GPs may point you to the NICE guidelines, and the local CCG policy, but the CCG interpreting the NICE guidelines, inaccurately ... So, you can challenge it. And I did some letters for a couple of members ... [OSG members asked me: can] you give me a hand? And I tell them how I approached it, you know, I take off my personal details and send them a copy of the letter” (Isabelle)*

This subtheme explored how participants performed many proactive activities to change the information and support provided to people with their T2D. They became active in their social circles and used their experience to make people aware of the condition and the optimal treatment options. Participants also tried to share their successful experience learned from the OSG with their HCPs so it could be shared with other people. However, not all HCPs were interested in their experience. They therefore approached a higher level within the health care system and joined the PPGs to try and change the information, treatment options and support provided to people with T2D. When some of the participants believed that they had the right to have access to a certain medical care, they approached the appropriate legal procedures to obtain it. They then shared their experience with other OSG members and encouraged them to familiarise with the legal guidelines and seek their rights. The influence of OSGs on the relationship that patients had with HCPs and the health care system is further discussed in Section 5.4.5.

### 5.3.2.3 Characteristics of OSGs for people with T2D

This theme examines issues related to the use of OSGs. In particular, it investigates how the use of OSGs impacted on participants, the negative issues they faced while using the groups and differences between the various OSGs that made them prefer one over others.



**Figure 5.5** Subthemes of the theme ‘Characteristics of OSGs for people with T2D’

These subthemes are presented in detail below.

#### 5.3.2.3.1 Drivers for people using OSGs

The use of OSGs helped the participants to obtain practical and emotional information that helped them understand the condition, be aware of various treatment options, set treatment plan, overcome barriers and achieve their treatment goals.

As explained in Sections 5.3.2.1.2 and 5.3.2.1.3, participants used OSGs to understand the nature of the condition, how it affected them, how their bodies reacted to different changes and how blood glucose tests can be interpreted:

*“I was looking for answers about things that worried me ... I wanted to know things like how [T2D] works and things like that and the forum gave me that sort of information. And if there was something new, I was doing then I wanted to know what it meant. So, you know like testing my blood and all those sorts of things. It's useful to talk to other people about whether they had problems and why does the blood initially rise in the morning with a Dawn phenomenon and all that sort of stuff” (Sarah)*

*“Much of [what I was looking for] was supporting information on what particular numbers mean and how to rationalise some of the information that you get so you know what the HbA1c figures meaning context, how long people have been working at it and how numbers change ... for me, it was mainly around understanding some of the numbers and some of the science behind it but more of a conversions and things were useful to understand” (Harry)*

*“[It helped me to know] what effect all different things have and just trying to understand the options and the success of the different options, I guess ... practical advice on actually how to do it. What things to look out for?” (Sophia)*

Participants explained that they obtained various types of information from the OSGs. They mostly sought information related to diet. They first learned what diet plan was appropriate for them. They then acquired practical information relating to that diet plan (e.g. meal recipes):

*“[the OSG] helped me ... finding alternative for my favourite breakfast, all of which were the highest carbs I ate ... So, I used it quite heavily to find substitutes for foods ... advice about how to cook, alternative foods, the breakfast issue” (Emily)*

*“[I was reading about] which foods are likely to be an issue which you know, where you might find hidden carb” (Sophia)*

*“I was looking for ways to make low carb eating delicious, and ways to control blood glucose but in a way that don't make life miserable, so you know a bit of exercise, times out, how to exercise, and what to eat and how to eat when you go out for meals” (Alice)*

*“It was food simply and cooking ... I am not a great cook, but I just do flour and then I find that flour is bad for me Oh ... I wouldn't know how to cook ... they educated me you know and ways of cooking I had not even considered” (John)*

They also used the OSGs to overcome barriers related to applying a diet plan. For example, one of the participants lived in a care home and was not able to cook. She therefore used the OSGs to acquire information on how to follow a low-carbohydrate diet without cooking.

Other interviewees explained that the OSGs helped them in knowing how to apply a diet plan while traveling or whilst having another health condition:

*“When I joined, I wanted kind of ways that I could eat low carb without cooking. Because I don't do cooking ... so I kind of explained that I can't cook for myself because of my living situation and that sort of thing. So, I was asking people for advice on how I can go lower carb and all that. So that one I found was really helpful for me, because literally, pretty much based on what people said to me there is what I started believing that I could actually do low carb” (Jessica)*



*“When I’m travelling, for example, that’s another big area, [I was] trying to find anything to eat when you’re away from home [on the OSG]” (Emily)*

*“[I was looking] if there were members using a LCHF diet who also had CABs and if their figures were ok” (Lucas)*

Participants also explained that OSGs helped them know about their legal rights, medications and how to tell other people that they have T2D:

*“[I was interested in finding information about] things like using medications at work, the rights at work, medications during different parts of your life like during pregnancy and things like ... diabetes and DVLA, like work rights” (Sally)*

*“[I was] trying to find out what other people’s experiences were in telling people that they got T2D, you know friends, family, work that kind of thing” (Alice)*

Besides the informational and practical support, OSGs provided emotional support to the participants. They explained that the OSG members supported them when they were discouraged and depressed. The encouragement and sympathy that they exchanged in the OSGs helped them overcome critical emotional situations (e.g., depression) that resulted from having the condition. The affirmation provided by other peers on the OSGs provided them with the power to continue with effective control and management of the condition:

*“If you’re feeling a bit down one day, you can put [a post] on [the OSG] and you know you’ll get uplifting messages from everyone you know, or if you’ve been a bit naughty and had something you shouldn’t, you know, it’s to get back on the wagon” (Mary)*

*“I mean, you can post a little bit of information about your successes, and you get some nice positive feedback, you know, if you’re not getting it from your doctors and the dietitian, it’s nice to get it from somewhere” (Emily)*

*“There’s people that have been there, they’ve done that they’ve been through it, they understand they sympathise empathise and they help you pick yourself back up ... [I’m using the OSG] to have somebody that actually understands what this is like? What a pain in the ass it can be. How hard it is to stay focused sometimes” (Sophia)*

Many participants explained that the use of OSGs helped them particularly to keep focused on maintaining their healthy habits. They used the OSGs to obtain motivation through sharing their daily activities. This made them feel accountable, focused and motivated:

*“I kind of post to 'what was your fasting blood glucose' [thread] every day that kind of keeps me accountable ... I find it keeps me accountable every morning, announcing your fasting blood sugars to a group of people ... It just keeps reminding you what you are doing if you keep feeding about diabetes every day, you're going to focus on it a bit more” (Jessica)*

*“[Being in the OSG] definitely does give me encouragement and I tend to look in it in the morning and it's definitely an encouragement for the rest of that day. You see, other people are doing it, I can do it too ... some days I think about having a couple of biscuits or something, and [I] just go on there and [I] can find somebody that's had exactly the same thing ... and you think oh, well, I don't want biscuits now” (Daisy)*

*“it's an everyday posting, that particular one. It's a thread that actually encourages people who low carb to put what I ate today, as a way to help them getting help from others and also as an accountability” (Sarah)*

As explained in Section 5.3.2.2.2, the use of the OSGs allowed the participants to be confident in their diabetes-related decision making. The experience and assurance exchanged with other members helped them to become confident in the information they had and the choices they made:

*“I've got more confident in what I'm doing and also saying about it, rather than waiting for [my HCPs] to ask me, which is not going to happen” (Sarah)*

*“The first year the forum was building out my confidence ... [it made me] much more confident. I am happy to talk to GPs about my diabetes” (James)*

*“It's really really scary going against your doctor ... making a stand against that is frightening. And sometimes you start to doubt yourself. So probably without forum, um, I would say I would have had a very different way of doing it ... [sometimes] I just come away feeling either stupid or unsure of myself. And I have to go back to the forum then to get the courage to carry on with what I'm doing” (Catherine)*

To conclude, the use of OSGs provided information to their users that helped them understand the condition, its complications and the treatment options available. This included practical information on diet choices and how to apply them, how to monitor blood sugar levels and how to overcome barriers. OSGs peers also shared information about the legal rights for people with T2D. The OSGs also provided a platform where members shared emotional support. Empathy, love, reassurance and encouragement were exchanged in the OSGs, which helped participants to be focused and confident in maintaining a good health.

The findings of this subtheme confirmed the findings reported in the previous study (Section 4.3.2.1), and it added further perspectives from the participants about the benefits of using the OSGs. They explained that the information and emotional support sought from the OSGs resulted in making them feel more confident and committed in the control and management of the condition. Engaging with other members on a daily basis helped them to keep focused on maintaining good health. The reassurance obtained from other peers on the OSGs made them feel confident about their diabetes knowledge and the treatment approach they decided to adopt to control diabetes. This was especially important when the approach was not supported by the information provided by their HCPs. This confidence made them feel more comfortable to manage the condition by themselves and minimise their dependency on HCPs. It also made them more confident when attending doctor's appointments about their decisions and treatment plans. This acquired confidence and experience with the condition contributed to turn them into active patients willing to share their knowledge and experience with others and change the guidelines provided to people with T2D (as explained in Section 5.3.2.2.4).

#### ***5.3.2.3.2 Negative issues in OSGs***

Besides the benefits of using the OSGs, the participants highlighted a number of negative issues they faced while using OSGs to obtain information and support. The negative issues mentioned were mainly the result of having conflicting information or engaging with OSG moderators or other members.

Participants explained that conflicting information contributed to making them feel uncertain about their decisions. For example, they read about different approaches to controlling their T2D by diet. The different and conflicting information they found on these diet plans made them feel uncertain and overwhelmed:

*“We have been told low calorie, low fat blah, blah, blah all our lives; and now you’re telling me high fat, low carbs! And then the medical profession is telling you: no, no, no, no, no; so it is quite frightening in a way!” (Oscar)*

*“I sometimes get a conflicting answer whereas sometimes that answer didn't make any sense ... I am not a 100% certain that I am doing the right thing ... I wonder if I am eating too much fats for example ... no one really knows the answer to that ... I think it does have an impact and it has had an impact on the forum and you know I have been a little bit disappointed it's been a negative side for me” (Andrew)*

Participants explained that some of the information they found on the OSGs might conflict with their previous knowledge, the information provided by HCPs or other information by other members in the OSGs. This, as a result, caused uncertainty on what the accurate information is. However, the uncertainty was influenced by the perceived norms of the community. As Section 5.4.3.2 explains, when OSG members encountered conflicting information, they tended to value the information preferred by the majority of other OSG members. This agrees with Li et al.'s (2021) findings, reporting that individuals' health behaviours are influenced by their perceived uncertainty and the norms of the surrounding community when encountering conflicting health information. However, as Andrew in the above quote explained, not all individuals can deal with conflicting information. The ability to deal with contradictory health information was linked to peoples' health literacy skills (Edwards et al., 2015). The exposure to conflicting health information was reported to decrease self-efficacy and response efficacy and, as a result, might also reduce the likelihood of making a positive behavioural change (Marshall & Comello, 2019). The exposure to a large volume of different information on OSGs might also lead to information overload that was reported to cause overwhelming feeling for OSG users (Turner, 2017).

Participants explained that questioning the information provided by other OSGs members that came from through their experience was one of the negative issues they had in the OSGs. They believed that every individual's experience is unique and believable; however, it might

not work for other people because they have different reactions to food, medications and physical activities:

*“[some members] tell people that they are wrong this isn’t working for them ... if they said it’s working why would you say they are lying ... so that’s what irritate me ... there is a brave phrase for that ‘for those who believe no proof is required and for those who don’t believe no proof would ever be enough’” (John)*

Other participants also explained that having strong arguments with other members made them feel uncomfortable in using the OSGs. They described other members as ‘argumentative’, ‘dogmatic’, ‘opinionated’ and ‘fanatical’. This mainly occurred as a result of one of the members being extreme in their beliefs regarding certain topics (e.g., the best diet programme for people with T2D) and not accepting other users’ opinions or experiences. These members did not present their information as coming from their own experience, but they presented it as a fact that should be generalised to, and followed by, the whole population. This resulted in putting the participants off from using OSGs. It might also have resulted in more serious health consequences, especially if it was related to sensitive topics such as medications:

*“I hate the dogmatism [members] that you do get in there and in other health forums. Somebody who describes himself as a carnivore [told me] you just lose your sweet tooth after a few weeks, and instead of saying this is my experience, [they said] this is the way it is” (Emily)*

*“I suppose that’s where the danger in those sorts of places comes or potential danger is that there’s people on those forums that are very, very strongly opinionated about things. That run may be counter to current medical advice and I suspect there’s people that go on to those forums and use them and take everything they read as gospel” (Harry)*

*“There were a few people who are a bit argumentative but in a less pleasant way ... because I think people can be a bit when they’re anonymous” (Catherine)*

While anonymity might be considered an advantage as it helps some users speak freely on OSGs, it is also considered a disadvantage as it encourages negative behaviours such as being impolite (Bender et al., 2013; Shoebottom & Coulson, 2016). As the above quotes show,

being anonyms might lead some members to be aggressive in their discussions. This, as a result, might create an uncomfortable space for many members. In more serious cases, anonymity might lead to other negative behaviours such as bullying and attacking others that disagreed with them. Inflammatory or hostile comments were also reported to be present in OSGs. Many participants explained that they had aggressive comments after they engaged in discussions with other OSG members. However, individuals reacted differently to the comments. While some of them were able to tolerate such behaviours, others were not and decided to leave the OSG:

*“I have had a couple of really nasty, abusive messages or posts aimed at me, and I’m fairly resilient to that kind of thing ... [I just] hit the Report button ... But not everybody is like that ... some people are very deeply upset by it ... I had a chat with one of the few people I have personal message with somebody who actually left the forum for a while because she’d been so upset by things directed at her” (Sophia)*

Turner (2017) explained that inadequate and harmful support (e.g. being dogmatic, argumentative, bully or aggressive) in OSGs might result from various reasons. First, because online communication lacks facial expressions and voice tones, misunderstanding, miscommunication and misinterpretation might occur between OSG members. This, as a result, might lead some members to be defensive as they perceived others’ comments as inappropriate/ impolite. Second, some posts that contain the suffering of others can be a source of anxiety for some members. When members, for example, express their negative health status or unpleasant complications, other members might feel that these negative consequences can occur to them as well and become anxious. This, therefore, might lead some of them to be aggressive and opinionated about their opinions.

Similarly, some members can be jealous by the successful progress of other members and become antagonistic. Lastly, some dominant members/ groups in the OSG might control the

majority of conversations in the community. Other members, as a result, might feel excluded or rejected, which might lead them to behave negatively toward others in the community.

Participants explained that OSG moderators intervened and stopped such comments. They reported that moderators should get involved when any of members became aggressive in presenting their opinion or when they became disrespectful to others:

*“It’s all down to the moderators of the forum of course ... so whoever the moderators, it should be really with them to ensure harmonious forum” (Andrew)*

*“These are not the things they are coaching to you are not facts, but I’m not going to say that I’m going to say my experiences. I do wish the moderators would intervene bit more and in those things” (Emily)*

However, other participants felt that the rules of the OSGs were too harsh. They thought that moderators did not allow them to express their opinions and feelings freely. They believed that the rules were exaggerated and influenced by the political beliefs of the OSG owners:

*“I am probably not going to last very long in the forum. I find the rules a little oppressive and the moderators heavy handed. They are concerned about not offending delicate sensibilities. I am more interested in making my life and those of others better, in differing actual personal experiences and debates about the science since we Type 2’s can be very different” (Lucas)*

*“I think at times moderation can be a bit swayed by political correctness, rather than other things ... Sometimes a bit over cautious in the moderation ... Wrong things will be deleted, or amended which perhaps overprotective a little bit” (Sophia)*

Matzat and Rooks (2014) reported two styles of moderation in health OSGs: positive (rewarding) and negative (punishing) moderation styles. In the first style, the provision of benefits is provided when a desired behaviour is performed. In OSGs, these benefits can be in the form of points, trophies or public appreciation of positively engaged members. On the other hand, the punishing moderation style removes the benefits when undesirable behaviour occurs. This can be in the form of deleting members’ posts, freezing their membership or

publicly disapproving their contributions. Tremblay et al. (2013) explained that although the provision of both styles of moderation is contingent on behavioural performance, punishments are perceived as being less fair than rewards. Matzat and Rooks (2014) also reported that rewards were reported to be more effective than punishments. They explained that although the punishing moderation style was perceived as more effective in avoiding inappropriate behaviours (not the stimulation of desirable behaviours), all punishing forms in this style were perceived as not effective by the participants of their study. Similarly, as the above quotes show, various participants did not accept the punishing moderation style and perceived it as “overprotective”. However, other participants (i.e. Emily and Andrew) desired more moderation to stop some negative behaviours that might annoy other members. Therefore, some participants believed that OSGs were not appropriate places for all people with T2D. They explained that many people could not use the OSGs to obtain the support they needed because of tensions, strong arguments and the presence of some aggressive members. These people, therefore, might need other forms of support:

*“I think it’s fair to say I am the type of person who does well on the forums. And there is a lot of people out there who don’t. And that chunk of population would probably need a different support network ... Sometimes on the forum there is tension and arguments. People who have dyslexia are disadvantaged; people who aren’t willing to fight their corner are sometimes disadvantaged” (Alice)*

This subtheme explored negative issues experienced by participants while they used the OSGs to obtain support. The participants explained that reading about conflicting information resulted in making them overwhelmed and uncertain about their health decisions. This resulted in making them feel exhausted and disengaged from their condition. Engaging in arguments with fanatical members also contributed to making the participants feel uncomfortable in using the OSGs. These particular members presented their experience as a fact that should be generalised to the whole population without considering personal differences between people. While anonymity was reported to encourage people to seek and



provide support and create non-judgmental online spaces (Taiminen & Taiminen, 2016), it also contributed to make some people unmannered and even aggressive in expressing their opinions or when communicating with other members. This resulted in making some participants annoyed and not willing to engage in discussions on the OSGs. The role of OSG moderators was described as essential in such situations. This confirms the findings of Jones and Meier (2011), who highlighted the importance of OSG moderators to ensure the protection and safety of the community and their users. While some participants explained that they hoped that moderators would intervene when the discussion became unpleasant, others asked for more freedom in expressing their opinions. They described the rules and restrictions enforced by OSG moderators as they limited their freedom to express their views. This shows how the rules were perceived in different ways by different OSG members. It also suggests that there is no common agreement on the level of involvement OSG moderators should have, although it might also reflect different approaches and different experiences in different OSGs. This highlights the findings of Windler et al. (2019), who reported that moderators were advised to balance punitive and interfering roles. The results here suggest that OSGs, therefore, might not be appropriate for all individuals in need of support because of the nature of online platforms. While some individuals might be able to tolerate OSG rules and unpleasant members, others might find it challenging and overwhelming to engage in such spaces. Moderation also needs to be handled carefully to maintain the desired balance.

#### ***5.3.2.3.3 Differences among different OSGs***

The previous subtheme explored how the rules of some OSGs were not favoured by many participants. This subtheme examines the various rules and cultures among the OSGs that led many participants to prefer an OSG over another or even switch from using an OSG to

another. OSGs will be referred to as OSG A, B and C in this section. The aliases were allocated randomly to ensure anonymity.

Many participants referred to the quality of information exchanged in various OSGs. They explained that they engaged in different OSGs and, based on the quality of the information, they preferred one over another. They described the preferred OSG as encouraging and a non-standard information provider. This OSG offered them alternative methods to address their condition:

*“I didn’t like [OSG A] general thing and then I just landed upon [OSG B] I don’t remember finding anything useful anywhere else ... I think [OSG A] was very conventional. Taking the conventional line, whereas when I got to [OSG B], I saw something different” (Catherine)*

*“I have browsed [OSG A] as well. But it seems generic. It’s not that helpful ... I would say it’s like the shop if I can compare it to a shop. [OSG A] is the pound shop and [OSG B] is Marks & Spencer” (Daisy)*

When comparing OSGs, participants mentioned three main aspects. First, they compared the quality of information provided in the OSGs. Many participants explained that they preferred OSG B because it provided alternative methods for treating T2D. The information provided in OSG A was described as promoting the NHS advice. It did not offer them alternative methods that helped them improve their health status. They explained that joining OSG A was useless because it repeated the information provided by their HCPs. Participants especially referred to the dietary information provided in the OSGs. They explained that, while OSG B suggested reducing the amount of carbohydrate intakes, OSG A promoted the Eat Well Plate and a diet that included a high amount of carbohydrates:

*“I found [OSG A] and I said that’s what I’m doing already [referring to Eat Well Plate] and you think there must be something better than that and then I found [OSG B] ... I was doing [OSG A] already, I still got diabetes and I tried you know going to [OSG B] and I thought I’ll try this the low-carb diet with nothing else has ever worked and then I started losing weight” (Mary)*

*“[I used OSG B] because [OSG A] got some really really rubbish diet advice” (Sophia)*

*“[OSG A] takes the line very much from the NHS gives mainly ... I just wasn't attracted by it; I just read it and it said the same thing and didn't offer me anything to make me [join their forum]” (Sarah)*

*“I reached [OSG A] as well but as you started reading the information and you say this is just so out of date” (James)*

*“[OSG A] kind of just reinforces what the [NHS] was all about and [OSG B] to be an alternate ... [OSG A] was probably the one I went to first they just repeated what [HCPs] told me and I said okay, and so after 6 weeks of the diet I got worse and I kind of felt that a messiah turned up and the messiah was the [OSG B] and I asked them and they said nooo! There's another way, try it have this eat yogurt try this have berries, not bananas or pears and it works for me” (John)*

Second, the participants compared the cultures of the OSGs they found. Most participants preferred an OSG with members that encouraged people to challenge themselves and the standard information they were provided with. They explained that they did not want to take medications and keep following the same lifestyle without introducing any changes to their life. They described that some OSGs had different values towards T2D. For example, some of them were more accepting of the fact that T2D is a progressive condition and there was a little that people with the condition could do to improve their health status. They, therefore, preferred an OSG culture that encouraged its members to make changes to their daily lives that helped them to control their diabetes by diet and exercise and without needing to be dependent on medications:

*“[OSG B] deals with it better than [OSG A] which is just be more generic ... I think [members in OSG B] took a different approach to what they were saying and trying to reject what the doctors are telling them and I kind of agreed on” (John)*

*“They may point you to the NICE guidelines, and the local CCG policy, but the CCG interpreting the NICE guidelines, inaccurately ... So, you can challenge it and I did some letters for a couple of members. But then suddenly, the administration on [OSG A] got a very sort of anti that ... other members came in and [they were] bullying [me]” (Isabelle)*

*“[I liked OSG B more than A because] when I first was diagnosed, I was adamant that I wasn't going to take any medications. I was going to deal with it diet and exercise and just the encouragement and the low carb diet plan, which is raised about on [OSG B] and the encouragement you can get” (Daisy)*

Some participants thought that the reason why the information and culture differed among the OSGs was that one of them was created especially for people with Type 1 diabetes. The OSG, therefore, generalised the information and culture to the T2D population without considering the differences between the two conditions:

*“It’s part of [OSG A]’s history ... they started of being a Type 1... and I think they have applied their mindset behind Type 1 which is occasional that is if you won’t take insulin otherwise you will die. They have applied that to diabetes and rather than saying, I think they can ... focus on what they know and what they have experience of and leave it up to someone else obviously at the gate of [OSG B]; but they are not going to do that because there are so many more Type 2s in the country” (James)*

*“[OSG A] is Type 1 centric and if you’re Type 2 using insulin, I don’t believe there’s any real support there for Type 2 diabetics like me who don’t use insulin or any of the heavier medications, its dietary advice is poor, very poor” (Isabelle)*

Others, however, thought that OSGs approached the condition differently because some of them were biased, as explained in Section 5.3.2.1.4. They mainly criticised the business model of these OSGs. They explained that biased OSGs were financially dependent on other companies. Their main income was from collaborations and sponsorships with food and pharmaceutical companies and which made them partial in their approach with T2D.

However, they explained that other OSGs were financially independent without the need to be sponsored by other companies. They could, therefore, provide a more effective approach towards T2D and, hence, attract more people:

*“[OSG A is] sponsored [by] the legendary, you know, [food company name] is one of their biggest sponsors. [pharmaceutical company name] are their sponsors ... They don’t have to work hard to get their money ... they have got, you know, sort of ... preferential treatment ... they were heavily criticised last year for entering a partnership deal with [company name], you know, the sort of sugary drinks manufacturers, and asked how they could justify it. Because obviously, you know, sugary drinks perfectly for me that would be the enemy. There is a lot there that I find questionable” (Isabelle)*

Third, various participants explained that they preferred OSGs that had more active members, were easily accessible and had a better categorisation of the content:

*“I did look up a couple of others, but they didn’t seem to be as active as this one, which is why I settled on the one I use” (Harry)*

*“The website that is much easier to access is supposed to be better in terms of finding information, you know, it’s such nice compartmentalise things and I prefer it that way ... and there are more people participate in that website than others” (Oscar)*

To conclude, participants showed a preference to OSGs that had more specific and detailed information about the control and management of the condition. They explained that they did not favour OSGs that advocated the information provided by the health care system because that information did not help them to make improvements. They therefore favoured OSGs that provided information on alternative methods to handle the condition. These OSGs also had a more challenging culture towards the condition. The participants illustrated that some OSGs had an accepting culture towards the condition and were willing to control the condition only via medications. However, other OSGs had a more challenging culture and their members encouraged each other to try alternative methods to control the condition by changing some of their habits (e.g. diet and exercise) without being dependent on long-term medications. Some participants preferred OSGs that were more active, easily accessible and had appropriately organised content. Further discussion on the role of the values and culture of the information source (e.g. OSG) is presented in Section 6.4.

## **5.4 Discussion of Interview Study’s Findings**

### ***5.4.1 Introduction***

This section discusses the results of the chapter in relation to prior research and knowledge. The section is structured based on the topic discussed. Further discussion of the findings of both this and the previous studies are presented in Chapter 6.

#### ***5.4.2 Participants' emotional reactions and opinions about information provision***

The literature reports that the diagnosis of a long-term condition is deeply emotional for patients (Buckman, 1992; Der Molem, 1999; Visser, 2017). The findings of the current study also indicate that the diabetes diagnosis caused emotional stress for most participants. The news made them feel shocked, angry, scared, worried and disappointed. This confirms the findings of previous studies reporting that people with T2D experienced significant negative emotional responses to their diagnosis, including shock, anger and anxiety (Beeney et al., 1996; Histock et al., 2001; Gillibrand & Flynn, 2001). Therefore, Choe et al., (2019) and Fallowfield and Jenkins (2004) recommended that HCPs communicate with patients carefully and consider patients' possible negative reactions when being informed of their diagnosis. Various strategies are used when communicating bad news to patients, including "preparing for the patients' visit, anticipating patients' feelings, building a partnership of trust with patients [and] acknowledging patients' physical and emotional discomfort" (Choe et al., 2019, p. 1). However, the findings of this study reveal that various participants were poorly informed about their diagnosis (e.g. through a short phone call from a clinic's receptionist) and that their potential negative reaction was not apparently considered.

Communication of information also includes preparing appropriate information by HCPs that matches a patient's level of understanding. The findings from this study show, however, that, when diagnosed, patients were provided with limited or no information about the condition, its possible consequences and treatment options. The participants in the study explained that they were eager to receive more information at the time of diagnosis. However, it is debatable whether providing information at that time was effective or not. The literature showed that the diagnosis is predominantly associated with the experience of shock for people with different long-term conditions (Buckman, 1992; Faulkner, 1998; Heisler & Friedman, 1981).

It also explained that the main feature of shock is “behaviour that shows failure of functioning and that indicates a degree or intensity of emotion with which an individual is unable to cope” (Jedlicka-Köhler et al., 1996, p. 205). Moreover, strong negative emotions have been reported as disruptive to memory (Loftus & Burns, 1982), so patients were usually unable to retain the information they were provided with when diagnosed (Der Molem, 1999; Kim et al., 2020). Whilst the majority of participants explained that they experienced strong emotional reactions to the diagnosis, they were not satisfied about the information provided to them. They explained that they were provided with limited or even no information. Some literature found that unmet informational needs for new patients might also lead to strong negative emotions. For example, Mesters et al. (2001) revealed that patients with greater information needs were associated with higher levels of depression and anxiety. These negative emotions might be caused by patients’ uncertainty and fear when they were diagnosed with the condition, as was the case with people in this study (as explained in Section 5.3.2.1.1). The unmet informational needs might also lead to negative health consequences. For instance, the findings (Section 5.3.2.1.2) showed that people who were not provided with information when they were in the prediabetic range, very often went to the T2D range. They explained that they did not fully understand the meaning and consequences of being in the prediabetic range and were not provided with practical information to help them to prevent the further progression.

This study suggests that there can be insufficient consideration of patients’ emotional and informational needs by HCPs when they communicate a diagnosis of diabetes. Section 5.3.2.1.2 explained that various participants in this study were frustrated at their diagnosis because of the negative impression they received from their HCPs following their diagnosis (e.g., they would end up at a later stage having to take insulin injections). While it is

important to highlight the potential complications of the condition, it is equally important to build hope and positivity. This confirms the recommendations of Choe et al. (2019) who reported that building resilience and giving hope at the time of informing patients bad news helped them to develop both physical and emotional strength and resilience.

More generally, in relation to the informational needs, the results emphasise the findings of previous studies (for example Sakai et al., 2017; Smith, 2003; Soni & Freeman, 2018) that patients should be provided written information that matches patients' levels of understanding in a stepwise format, on a timely basis and starting from the time of the diagnosis. This study adds to the literature that providing information about OSGs would help patients to get more continuous information from their peers that would match their current informational needs. The availability of the OSG 24 hours a day could help meet their immediate informational and emotional needs. All of this information would fulfil patients' initial and following informational and emotional needs and have health positive outcomes for newly diagnosed patients. Although some HCPs might question the quality of the information available on OSGs and, therefore, might be reluctant to inform patients about OSGs, the next section explains that OSG communities were able to validate and enhance the quality of exchanged information.

#### ***5.4.3 Information trustworthiness***

As discussed in Section 5.3.2.1.4, various factors influenced how the participants trusted or distrusted the information obtained from their HCPs or OSG. This section will discuss trust first in relation to HCPs and then in relation to OSGs. In relation to the latter, it will consider the influence of structural features (such as the website business model) on trust, as well as



the role of trust (or lack of it) among members of the OSG. Specific details about the website business models were not provided to ensure anonymity.

#### ***5.4.3.1 The influence of OSG information seeking on trusting HCPs***

Regarding HCPs, the findings show that participants altered their HCP-recommended treatment plan when they discovered alternative information on the OSGs. Most of them were not concerned about the source of the information as long as they felt that the information was effective. This confirms a previous study reporting that the quality of online health information influenced how patients trusted their HCPs more than its source (Lu et al., 2018). The results of this study also confirm the findings of the previous one (Chapter 4) that experience-based information was preferred over that based on medical evidence. In other words, personal experience may be a more important factor than empirical research/science in determining how people trust information. This may resonate with a wider cultural phenomenon, namely, that there is evidence of declining trust in expertise information when it is inconsistent with the endorsed personal experiences of other people (Hocevar et al., 2017). Moreover, this study reveals that the participants, when discovering more effective information, came to believe that the information from their HCPs was outdated, which led patients to distrust HCPs. The experience-based information shared between and among peers in the OSGs influenced the credibility of HCPs negatively and, as a result, weakened the relationship between HCPs and some of the participants. Exploring more effective treatment plans on the OSGs led to patients questioning the validity of the HCP-recommended treatment plan/information and whether it reflected the most up-to-date knowledge. Whilst the literature (e.g. Ahluwalia et al., 2010; Gualtieri, 2009; Helft et al., 2003; Tan & Goonawardene, 2017) has outlined that HCPs trust might be negatively influenced as a result of obtaining online information, to the author's knowledge, this is the

first study that has explained why trust in HCPs was affected for people with T2D using OSGs.

#### ***5.4.3.2 Trust influencing factors in OSGs***

Feng et al., (2004) and Zhao et al. (2013) reported that trust is a key component in the facilitation of information sharing in OSGs. Lovatt et al (2017) reported that trust in OSGs operates in three dimensions: *structural*, which concerns the affordances and rules of the OSG; *relational*, which concerns how the interaction with other OSGs users influenced trust; and *temporal*, or how time spent in OSGs influenced trust. The findings in this study confirmed that the rules of the OSGs and activities of the moderators influenced how trust was perceived by their members. Various participants explained that the welcoming messages they received from the moderators when they posted for the first time contained information about the conditions and guidelines that helped them navigate through the large amount of information in the OSG. This contributed to their building confidence and trust in the community. Additionally, interventions by moderators to protect OSG members and the community (e.g., to prevent bullying or to relax the tone in controversial discussions) made the participants feel safe in using and trusting the OSG. On the other hand, many participants described how they came to distrust OSGs in which moderators prevented them from sharing their opinions. They disengaged from the OSG because its moderators did not allow them to express their views freely. Their views were controversial or not in line with the NHS advice. The interventions of moderators were mentioned repeatedly in the interviews as a factor that led members to minimise their engagement with the OSG.

The findings from the interviews contribute further aspects on the structural dimension of trust. The results indicate that the OSG's business model and association with other

organisations might influence the level of trust that members had in the OSG. Participants explained that observing cooperation (e.g. sponsorship) between the OSG and other commercial parties (especially food and pharmaceutical companies) negatively influenced their trust of the OSG. Connections with commercial parties resulted in participants perceiving the information presented in the OSG as biased, and hence as potentially untrustworthy. The business model of the organisation that owns the OSG (e.g., whether it was a profit-making or non-profit organisation) also appeared to influence how members trusted the OSG. Participants perceived organisations that had full charitable status as being dependent on other commercial companies to provide financial support, which meant that the information provided in that OSG would be biased. Moreover, the participants explained that these organisations have guaranteed income from their sponsors, so they would not have to compete to provide high-quality, effective information. Other OSG organisations, on the other hand, had to provide effective and up-to-date information to attract online users and build community large enough to generate income. While previous research has reported that the affiliations and advertising carried by health websites influence their trustworthiness (Fogg et al., 2003; Hargittai et al., 2010; Sbaffi & Rowley, 2017), to the best of the author's knowledge, this is the first study that outlines how the business model of OSG hosts and their associations (e.g. through sponsorship) with other organisations play a major role in how users judge the credibility of the OSG and the information exchanged in it. In particular, these factors were perceived to influence the quality of the information provided and how biased it may be. The information exchanged might be biased towards the sponsoring parties and the guaranteed income meant they would not need to make an effort to provide up-to-date practical information.

Relational (e.g., interpersonal factors among peers) and temporal aspects also played an important role in building trust in OSGs. Information shared in OSGs involves personal and experience-based information that has been reported to require strong ties with information providers and higher level of trust (Fan et al., 2019). Lovatt et al. (2017) explained that time spent in the OSG played an important role in developing trust among peers. The results confirm that established members, who were more familiar to other OSG users, were more trusted than new members. This study adds to the literature other aspect of the *relational* dimension on how trust develops between OSG members in that most participants performed a number of steps before accepting the information from their peers. Some of them built a trust relationship with other members over time. They would start in the OSG with caution and would check other sources to verify the credibility of the information in order to build a trusting relationship with the person posting as an information provider. Others, however, tended to rely on the “wisdom of the crowd” to confirm the information exchanged in the OSG, especially if it was personal or experimental. They would pay attention to the number of replies to posts, and especially to the number of people who agreed or disagreed with a member. On that basis, they would then accept or reject the information.

Other participants, on the other hand, valued members who reported positive progress and shared it on the OSG. They would perceive their information as credible, since it came from successful experience. This suggests that some members, based on their reports of their experience, were perceived as more trustworthy than others, because they had positive health improvements and shared it on the OSG.

In conclusion, the results highlighted three areas influencing trust in the process of obtaining information from OSG. First, the information exchanged in the OSGs made the participants

explore wider resources about the condition and its treatment approaches. This resulted in participants questioning the quality and credibility of the information provided by HCPs. Second, structural aspects of the OSGs contributed to how trust was perceived. Moderators' posts, particularly welcoming posts that continued intimate messages and guidelines that helped them to navigate through the massive amount of information in the OSG, contributed to building confidence and trust in the community. Their interventions to prevent negative behaviours (e.g. bullying) and misinformation were also favoured by the participants and made them feel safe to belong to the community. However, if moderators intervened to close down discussions or prevent certain opinions from being expressed, this would lead participants to question the credibility of the OSG and to some members disengaging from the community. Therefore, a balance is needed between maintaining a positive environment and not being too interventionist. The business model adopted by the OSG and its association with other companies influenced how the participants perceived the quality and credibility of the information shared.

Finally, participants varied in how they trusted other OSG members. They were individualised in how they did this: they tended to build trust with individual members rather than with the entire community, they relied on other members to confirm the information and they judged the credibility of members based on their shared progress. These three methods intersected with each other and did not operate in isolation. For example, the verification of shared information by other members might outweigh the opinions of members who reported positive progress or with whom participants had established a personal trusting relationship.

#### ***5.4.4 Different uses of OSGs and user behaviours***

Participants differed in how they started using the OSG and their subsequent relationship with it. Most participants had informational needs that led them to search for information on the Internet. They then found the OSG that attracted them and so they joined it. However, one of the participants, after finding an OSG, thought that they were too old to join such a community. They were not familiar with OSGs and were convinced that these communities were widely used among the younger population. Huber et al. (2018) reported that older people were attracted to face-to-face support groups whereas younger people preferred OSGs. However, the data from the interviews suggests that introducing older people to small closed online communities (such as the one they used in the structured online course mentioned in Section 5.3.2.1.3) encouraged them to join larger open OSGs subsequently. This might help them to overcome their fear of posting in an open space that contains thousands of members and to build confidence in joining larger OSGs that help them to fulfil their informational and emotional needs.

A key finding of the current study was that, while all the participants joined OSGs to fulfil their informational needs, they differed in how they approached them afterwards. Some of them limited their use of OSG on further information seeking. They used OSGs mainly as problem-solving platforms. They would use them only to ask their peers when they needed information and feedback on their original posts if they had further queries. Others, however, felt that they were part of the community and engaged more with its members at a different level (e.g. socially). Many of the participants kept using the OSG on a daily basis to log their activities (e.g. food consumed, blood sugar levels, physical activities), and sometimes this use extended over several years. In this way, they connected with other members and built relationships in the community that encouraged them regularly to focus on the control and

management of their condition and support when they were discouraged. Gilbert et al. (2012) reported similar finding that OSG peers offered an ongoing social and emotional support that helped other members to stay motivated in managing Type 1 diabetes. This current study has highlighted that while some members needed this ongoing support until they gain control on their diabetes, others, however, sought this support for longer time (e.g. several years).

Some members, after satisfying their informational needs and gaining experience in how to control and manage their diabetes, became information providers in the OSG. They explained how it was especially important to help new members, since it was reciprocating the support that they had received when they first joined the community. Lovatt et al. (2017) explained that reciprocity culture is common in health OSGs. The current study provides insights on reciprocity for the members in these OSG, and shows that reciprocal behaviours were not limited to giving back to the OSG, since many participants demonstrated reciprocal behaviour towards an extended population beyond OSGs. After achieving a good health status and having benefited from the knowledge and support exchanged in the OSG, they then tried to spread the knowledge and share their experience offline as well. For example, they engaged with their local GPs and Patient Participation Groups to change the information provided to people with T2D. Having received help from OSG members that led them to an improvement in their own health, these members felt that other people also deserved to have better information. Small et al. (2013) reported that empowered patients showed willingness to assist peers with similar health problems. This is the first study to show that the reciprocity culture in OSGs might not be limited to helping other OSG members only. OSG members might react to the support received from other OSG members, as well as to the reciprocity culture of the OSGs, by giving back more generally to the T2D population, whether online or offline.

Other participants explained that they kept using OSGs even after they had fulfilled their informational needs because they enjoyed using them. They reported that, since they were retired and had spare time, participating on the OSGs became their hobby to spend time and stay connected with other members. This confirms the findings of Yang et al. (2017), who reported that cancer survivor OSG members' long-term commitment to the community related not only to their informational and emotional needs but also to their social needs. Once members built connections with other peers in the OSG, they kept using the OSGs even after their informational needs had been satisfied. The current study highlights that this is potentially especially important for older people who have free time and use the OSG to socialise with their peers. Section 6.3 outlines the different roles OSG members had as identified by the study.

To summarise, this study has shown how OSGs were perceived and used by the participants. OSGs were regarded by a participant as being appropriate only for the young population. The study suggests that using small closed online communities might help older people to see the benefits of using such communities, which would subsequently lead to them joining larger open OSGs. The study also reveals that OSGs were used differently by different members. For some participants, they were primarily problem-solving platforms; for others, they were a source of daily motivation and encouragement that helped members to focus on the control and management of the condition; and for others, they enabled socialisation with other people. The latter was particularly observed among older people who had limited social life outside the OSG. The study also reports that reciprocal behaviours occurred widely among members of the T2D OSGs. Members would, in time, become information and support givers to other members in the community. The most interesting finding is that this reciprocity



extended to sharing information and support beyond the OSGs. As a result of the support they obtained from the OSGs, members reported that they actively wanted to share their knowledge with a wider population of people with T2D, both within the OSG and beyond it.

#### ***5.4.5 OSGs' influence on patients' relationship with HCPs and the health care system***

The findings indicate that information seeking on the OSG had implications for the relationship between patients and HCPs and, more generally, between patients and the health care system. Lu and Zhang (2019) reported that OSGs have positive implications for patient-doctor relationships. However, the current study suggests that this is not always the case. The information exchanged between peers in the OSGs led members to discover aspects related to the management of the condition that they were not aware of. For example, they learned how carbohydrates might influence their blood sugar levels and how various diet plans use reduced carbohydrates intake to control the condition. They also learned that guidelines related to T2D (e.g. self-monitoring-related prescriptions) might be interpreted and, therefore, applied differently, by individual HCPs.

This had a significant effect on their relationship with their HCPs and the health care system. As explained in Section 5.4.3.1, for example, participants had different perceptions of the knowledge and care provided to them by HCPs. This suggests that informational and experiential discussion occurring in these online communities might have educated the OSG members, enhancing and improving their awareness, knowledge and understanding of specific health and legal topics. The knowledge they acquired may have seemed to be very different to that provided by HCPs and the health care system. This fractured the relationship between patients and their HCPs in particular, and the health care system in general. Since the beginning of their journey, many participants reported that there was a tension in this

relationship. For example, when they attended the HCP-led educational course that was prescribed to them following their diagnosis, most participants explained that they had disagreements with the course instructor because the information provided was different from that available in the OSG. This was reported only by participants who sought information from the OSGs prior to the course. This confirms the findings of Snow et al. (2013) that, when attending such educational courses, UK patients with Type 1 diabetes who were knowledgeable about the condition, received negative reactions from HCPs who were unable to deal with informed and empowered patients. As explained in Section 5.3.2.1.2, this resulted in a collision between the course attendees and instructors, which may in turn lead to the patients distrusting HCPs.

The results suggest that the use of OSGs encourages members to demonstrate empowerment in their relationship with their HCPs. Knowledgeable participants were more certain about the information they had gained about the condition and the health care system. Armed with this increased knowledge, they challenged the system, encouraged others to be activists, engaged in community groups for patients to make their voice heard, and demanded more treatment options and wider information. For example, as discussed in Section 5.3.2.2.4, when participants challenged the system to prove their eligibility for certain prescriptions, they shared their experience with their peers in the OSGs and encouraged them to assert their rights. This suggests that use of OSGs might change the attitudes of patients which, in turn, will alter the traditional relationship between patients and health care providers.

In the new form of relationship, patients have a wider knowledge about their condition, treatment options and the health care system, based on their own experiences. This might lead to negative encounters with HCPs who are not prepared to work with such patients.

Loane and D'Alessandro (2014) found that empowered and knowledgeable patients who use OSGs challenged the traditional asymmetric relationship between patients and HCPs. This type of empowered patient demanded a partnership rather than experiencing a paternalistic relationship with HCPs. The current study shows that the majority of HCPs failed to provide such a partnership. The participants who were fortunate enough to have HCPs that worked with them in a partnership showed appreciation for this and described the relationship as positive and strong. In such partnerships, the HCPs respected participants' choice and performed a more consultative, rather than instructional, role. The perception of the HCPs, and their reaction to the autonomy of the participants, affected their relationship with patients. The relationship with those HCPs who did not endorse and legitimise the decisions made by participants shifted to become operational: participants visited their HCPs to refill their medications or to conduct occasional blood tests, but without engaging in a real discussion with the care provider. The participants thought that there was no purpose in engaging with HCPs about their health, since they had different beliefs.

The findings of this study contradict those of Graffigna et al. (2017) who reported that the support given by HCPs to the autonomy of their patients influences the active engagement of patients within their health care. The results of this study showed that the engagement of participants with their health was not affected by the position of the HCPs to the decisions made by patients when the decisions were encouraged and endorsed by OSG peers. They appreciated having a supportive HCP, but not having one did not influence their engagement and activation in their condition because they obtained support from OSG peers. This highlights the importance of the informational and emotional support members receive from their OSG peers, especially when the decision/treatment option is controversial and is not in line with the general health care system advice (e.g., following a low carbohydrate diet).

In summary, OSGs influence the relationship between the patients and their HCPs.

Information exchanged among peers altered the perceptions of patients about certain topics which, in turn, impacted on their relationship with their care providers. It increased their involvement in making decisions related to their T2D that might have not been in line with the recommendations made by their HCP. The use of the OSGs might change the attitudes of patients. OSG use can make patients better prepared with knowledge, and more likely to challenge information and treatment options, become activists and encourage activism. This suggests that the use of OSGs might improve the patients' sense of empowerment. Although HCPs reacted to this change in the relationship with their patients in different ways, those who were willing to form a partnership with their empowered patients had a positive impact on them. The attitude of the HCPs towards the autonomy of the patients was not seen to have an influence on their engagement and activation levels in health care while supported by OSG peers.

## **5.5 Conclusion**

This chapter has described the second part of the study in this thesis. The study contributes to the knowledge on information behaviours of people with T2D using OSGs. In particular, this chapter has discussed how participants sought information and navigated among various information sources to fulfil their needs. It has also explored how they utilised the information and how this influenced their health behaviour and empowerment. This involved looking at various important aspects, such as information trust, patients' emotional reactions to, and opinions about, information provision, their relationship with doctors and the health care system, different behaviours and roles in using OSGs, and positive and negative

activities occurring in the OSGs. The analysis of the interview data identified three main themes, which are summarised below.

In relation to information and knowledge, the findings showed that the participants were provided with little or no information at the time of diagnosis. Moreover, their potential emotional reactions to the diagnosis were not carefully considered, which, along with the absence of information, led to strong emotional reactions to the diagnosis. The information needs resulting from the diagnosis led patients to seek information from various sources, including OSGs. While their experiences of information seeking varied, the early searches helped them understand the nature of the condition, how others coped with it, and what treatment approaches were available to them. This had positive effects on their health outcomes, but negative effects on their relationship with their HCPs when the latter did not agree with the approach.

The patients' navigation through various information sources also involved forming a judgment on which information providers to trust. The alternative methods of treating T2D led the participants to have equal communication with HCPs, as well as to question the knowledge of their HCPs. However, HCPs who provided and supported alternative treatment methods and involved the patient in choosing the appropriate ones were trusted and favoured. The study also yields significant findings in relation to participants' trust in other OSGs and their members. Participants favoured OSGs that provided alternative treatment options and that were not biased towards a specific method. The findings suggest that trust among OSG members is built among individuals rather than the whole community. At the beginning, the information provided by a member would be validated using other sources. Over time, if this member sought to provide valid and credible information, they would be trusted intrinsically.

Participants relied on other members to confirm the information, and they tended to trust those members who had made positive progress in managing their condition.

As patients with T2D, the participants listed various factors that motivated them to seek information relating to their condition and to become actively engaged in the management of the condition. These factors ranged from physical to social and cognitive motivations. The motivating factors contributed to increasing patients' awareness about the seriousness of the condition and its complications, as well as the existence of alternative effective treatment options that might help them to have better health outcomes. Likewise, they reported that physical, social and cognitive factors also demotivated them from being active in seeking and using information related to their condition. The hindrance factors absented the presence and seriousness of the condition. They also limited their awareness of other possible treatment options and their effectiveness. The use of OSGs influenced their beliefs and behaviours relating to T2D. Most participants reported that the experiential knowledge exchanged in OSGs contributed to them changing their perception of the best approach to control and manage the condition. They realised that changing their habits (e.g., diet or exercise), together with continuous monitoring of their blood glucose levels, was the best and most effective way to achieve positive health outcomes. They explained that this also changed how they thought about the condition, no longer seeing T2D as dangerously progressive and as having to be controlled through medication.

This study has explored how participants utilised the information obtained from OSGs. It showed that they mostly sought information before performing a new action. The performance of new action created further information needs about the performed action. After performing a new action, the participants provided feedback to their peers with more

questions or experiences. The application of a new health action was always accompanied with an active monitoring of blood glucose levels to evaluate the action's impact. After the participants achieved a good level of understanding about the nature of the condition and had a successful experience with it, they became information providers in turn and got involved in several activities to change the information and care provided to people with T2D. Moreover, their understanding of, and experience with, the health care system and its guidelines led them to encourage others to be activists and to assert their rights.

This research has also looked at the positive and negative activities occurring in the OSGs and how the participants preferred one OSG over another. Besides the practical and emotional support that was exchanged, OSG members provided confidence and reassurance about the approach they recommended to control and manage their condition. This confidence helped establish the basis for equal communication between the participants and their HCPs. On the other hand, conflicting information in the OSGs caused uncertainty for various participants and left some feeling overwhelmed. The exposure to ill-mannered and aggressive OSG members resulted in an unpleasant experience for some participants and contributed to their becoming less engaged in the community. Generally, most participants favoured OSGs that did not simply promote the information provided by health care system, but also supported a wide range of alternative information and treatment options. In addition to being influenced in their choice of OSG by the nature of the information exchanged within the group, participants also preferred OSGs that had a culture of challenging, rather than accepting, the condition.

This chapter has discussed some of the findings in relation to the literature; the next chapter (Chapter 6) will triangulate the findings of this and the previous chapter, and it will discuss

them with regard to related information and health theories. Chapter 7 will then conclude the thesis, discuss the limitations of this study and present the implications and recommendations for practice and for future research.



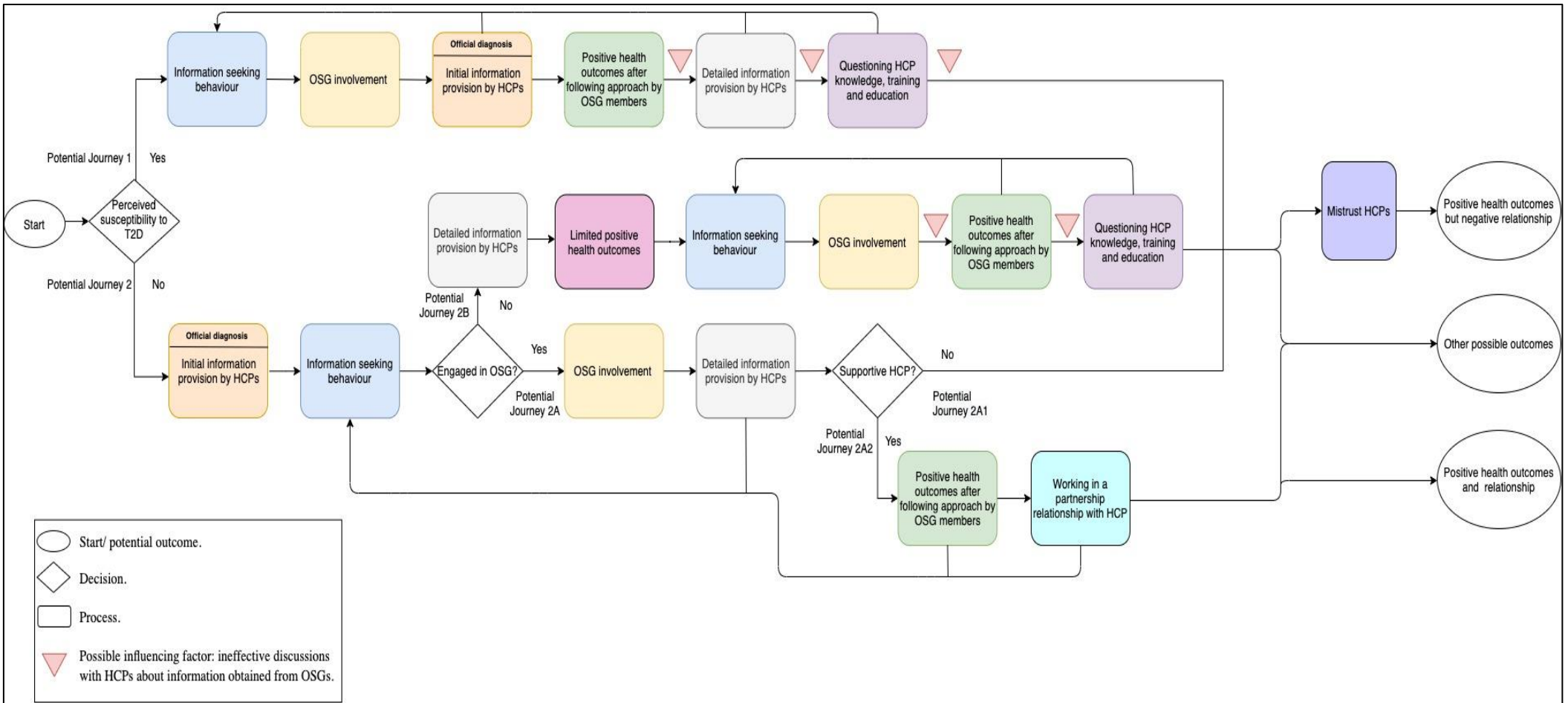
## **CHAPTER 6 : DISCUSSION**

### **6.1 Introduction**

The previous two chapters presented the findings of the two studies of this research: the study on the analysis of posts from three diabetes OSGs (Chapter 4) and the interview study with seventeen people with T2D using OSGs (Chapter 5). This chapter synthesises the findings of both studies and discusses how they relate to the extant literature and how the research contributes to original knowledge in the field. The chapter first presents the information journey of the participants to the study before discussing this in relation to various theories and models (Section 6.2). Chapter 6 then explores the various online behaviours and roles of OSG members identified in the study with the utilisation of related theories to understand the findings (Section 6.3). Finally, the chapter brings together all factors identified in the thesis that are found to influence patient empowerment and discusses them in relation to the Health Care Empowerment Model (Section 6.4).

### **6.2 Information behaviour for people with T2D using OSGs**

The two studies in Chapters 4 and 5 showed that people varied in how their information needs were developed and how they fulfilled them. Figure 6.1 presents a diagrammatic representation to summarise the information journeys for the people participating in this study. The discussion below is divided based on the sub-topics occurring in the diagram.



**Figure 6.1 The information journey identified in the study**

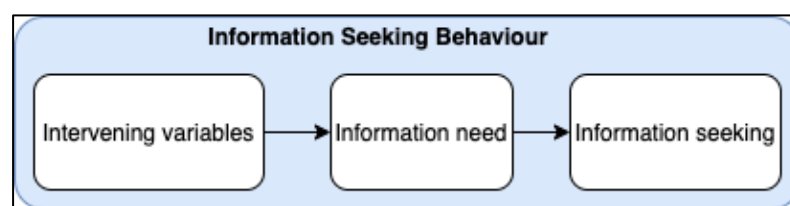
### ***6.2.1 Motivators to seeking and using information and making a health action***

As the potential journey 1 shows, this study found that the perceived susceptibility and seriousness of the condition contributed to increasing some participants' perceived risks of the condition and its consequences and, as a result, start their information seeking journey. This was explained by the HBM, where the perceived susceptibility refers to an individual's subjective perceptions of the risk of developing an illness (Janz & Becker, 1984). Rosenstock (1966) explained that the model argues that people will not take a health action unless they feel susceptible to the condition. This is the main difference between participants in potential journeys 1 and 2. Conversely, participants in the potential journey 2 did not feel susceptible to the condition; therefore, they did not take any action until they were officially diagnosed with the condition.

The perceived seriousness of the condition refers to individuals' evaluations of the perspective consequences of the health condition. The HBM model suggests that the stronger the evaluation of the consequences, the more likely the individual will act to prevent them (Carpenter, 2010; Rosenstock, 1966). When individuals feel susceptible to the condition, but perceive it as not being serious, they are less likely to take action. For example, Andrew, from the interview study in Chapter 5, knew about his susceptibility to the condition, but perceived it not to be too serious. Therefore, initially, he did not take any action to harness the condition and its consequences.

Information seeking behaviour for participants in the current study might have been influenced by various intervening variables (as shown in Figure 6.2), related to Wilson's model here. These intervening variables (explained in Section 5.3.2.2.1, Figure 5.4) both encouraged and discouraged individuals from seeking and using information to improve their

health status. While the study in Chapter 5 explained various physical, social and cognitive factors that influenced individuals' information seeking and use, Wilson's model reported various psychological, demographic, interpersonal, environmental and source characteristic factors that might influence people's information behaviours (Wilson, 1999). The factors identified in the Interview Study were similar to those identified in Wilson's model. Figure 6.2 below shows the sequence result of the intervening variables/factors.

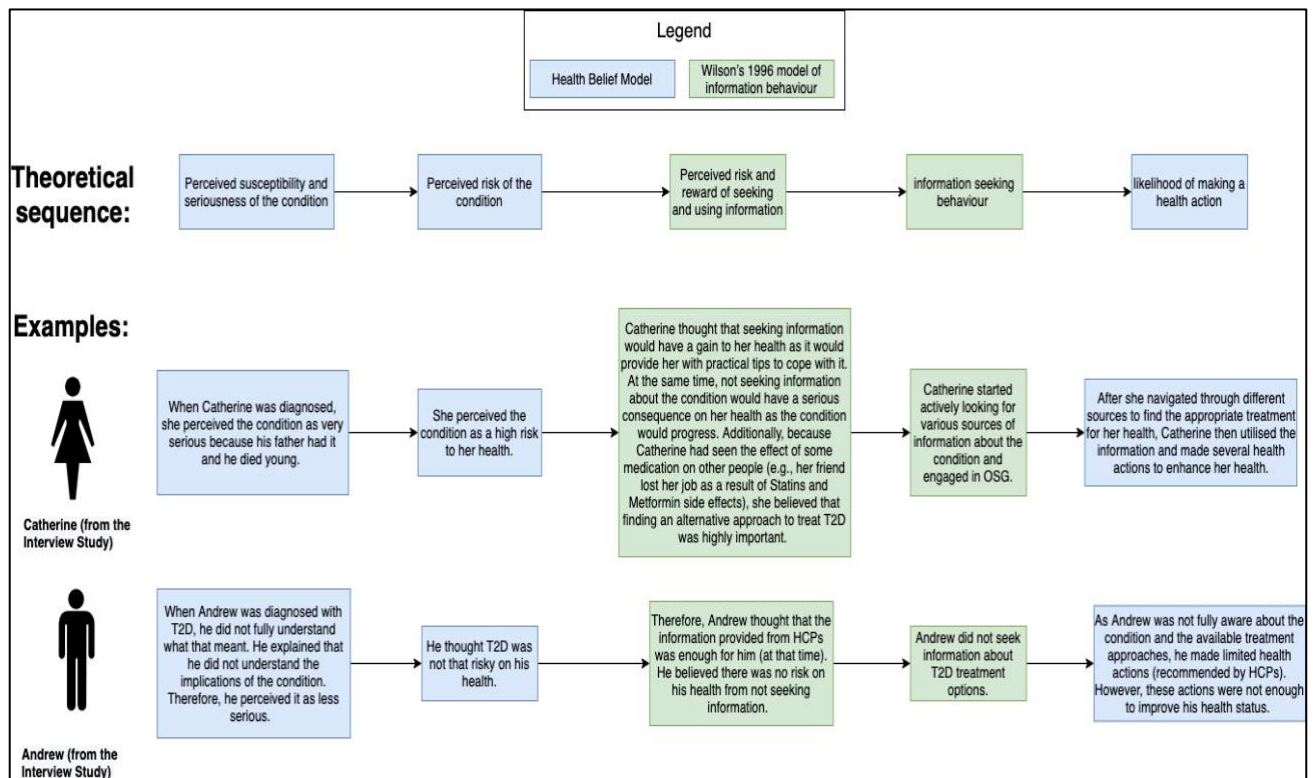


**Figure 6.2 Information seeking behaviour sub-processes identified in the Information Journey of the present study**

These factors might play a supportive, as well as a hindering, role in information seeking and use. For example, previous experience with, and knowledge of, diabetes might increase an individual's awareness about its seriousness. Therefore, they might be more likely to seek and use information. On the other hand, the lack of knowledge and experience might contribute to perceive the condition as being less serious and, therefore, take no action. Moreover, Wilson's model identified other elements that influence information seeking behaviours, such as the Risk and Reward Theory, which states that people are more likely to seek information if the perceived gain (e.g., the comfort of eliminating uncertainty) in performing the process is increased. The Risk and Reward Theory can be seen as similar to the perceived susceptibility and seriousness of the condition in the HBM. They both act as a motivator or demotivator based on an individual's realisation of the perceived risk gained from not performing a certain action. However, the main difference here is that the Risk and Reward Theory was used in Wilson's model as a factor to influence information behaviour

while the perceived susceptibility and perceived seriousness in the HBM influence the likelihood of performing a health action.

The present study shows that both constructs occurred for the participants. Prior to performing a preventive health action, information about available health actions and their effectiveness was needed. Therefore, the constructs of the HBM occurred first as stimulators of information behaviour constructs. However, its outcome (the *likelihood of making a health action*) occurred later (Figure 6.3).



**Figure 6.3 The sequence of the occurrence of information seeking and health action motivators and hinder identified in the present study**

As shown in Figure 6.3, health concerns (the perceived susceptibility and seriousness) acted first as provokers to the evaluation of the reward and risk of seeking, selecting and using information resources. This shows that both the HBM and Wilson's model were useful in

understanding an individual's health and information behaviours. This also suggests that their constructs might be connected in some cases as shown in Figure 6.3 above. This is especially important for individuals for whom the perceived risk of the condition contributed to an increased likelihood of seeking and using related information. For other individuals, their perceptions of the susceptibility and seriousness of the condition might have resulted in performing a health action (e.g., as recommended by HCP) but not necessarily seeking and using information. This was the main difference between the participants of the present study and individuals whose perceived susceptibility and seriousness of the condition did not encourage them to obtain and utilise information from different sources.

### ***6.2.2 Selection of Information sources***

Recently, Hadjiconstantinou et al. (2020) reported that access to, and the availability of appropriate resources and knowledge of the condition are considered the main components necessary for successful self-management of T2D. While most search engines return high-quality results regarding health information, the selection of information sources is very important, because it could have a direct impact on people's health decisions and behaviours (Kitchens et al., 2014). When the participants in the present study started their information journey, they explored various online sources and were in a position of information/source selection. They explained that most sources presented content similar to the official information provided by their HCPs (e.g. recommending the Eat Well Plate diet). Therefore, they preferred the sources that presented alternative treatment methods such as reducing carbohydrate intake and continually self-monitor blood sugar levels. Even when discovering various OSGs, most participants preferred those that presented alternative approaches towards diabetes and not those that simply restated the recommendations made by the health care system. They explained that they did not agree with the recommendations provided by

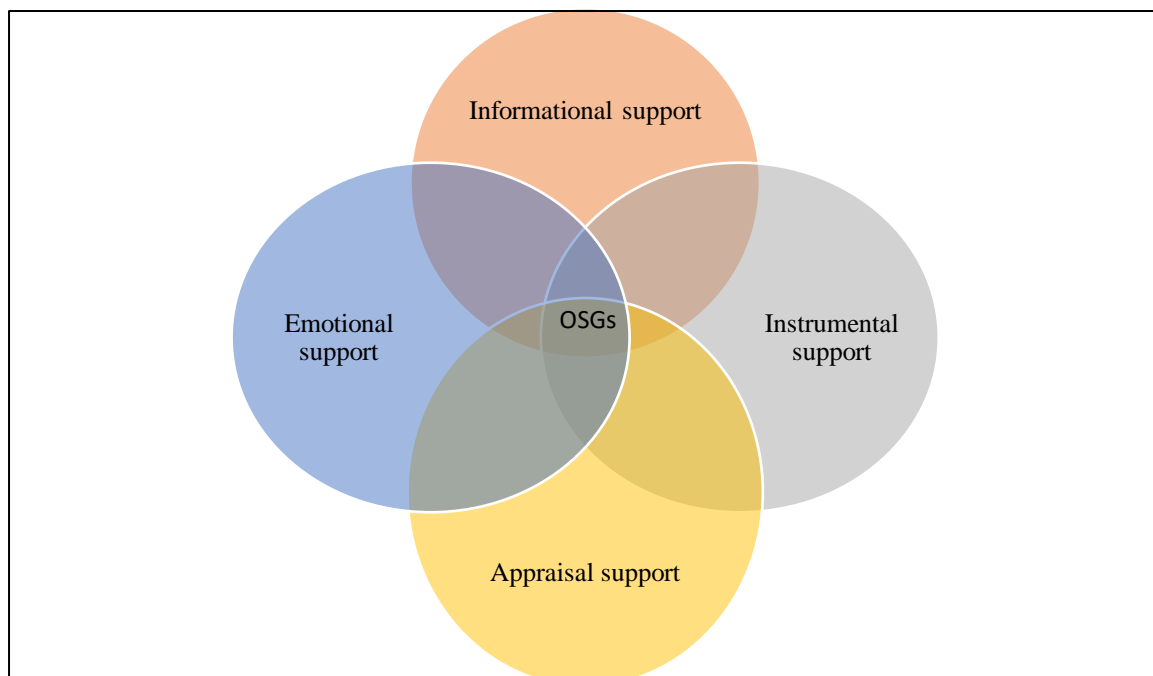
HCPs and used the OSGs to learn about alternative approaches. For example, they did not agree with the amount of carbohydrates intakes advised by HCPs and, therefore, they sought alternative diet options on the OSGs. This contradicts the findings reported by Chi et al. (2018), who explained that health information seekers generally preferred online information generated by HCPs. This also shows that the OSG users in this study had different needs and information selection criteria compared to other Internet users who preferred HCP-generated content.

The current study reported various reasons behind the decisions made by OSG users to select one or more OSGs as an information source. First, as illustrated earlier, the personal and experimental knowledge exchanged in the OSGs introduced alternative approaches to deal with the condition, which made OSGs unique information sources. This is especially clear for users that joined OSGs supporting and encouraging the use of alternative methods. They explained that other users' unique personal experiences with the condition attracted their attention when exploring various sources. This confirms the findings of Zhang et al. (2017), who reported that OSGs were mostly selected for exploratory and personal experience information tasks. Second, successful stories and experiences shared between OSG members encouraged new users who were exploring the community with the intention to join it. They felt that, if other people were able to improve their health status by following certain methods, then this would also be possible for themselves:

*“You see, other people are doing it, I can do it too” (Daisy – interview study).*

Joining online communities with other people who shared similar health goals was associated with positive health outcomes (Allman-Farinelli & Nour, 2020). Other people in such communities acted as role models whose success encouraged other members to follow in their footsteps and to engage with their own health (Allman-Farinelli & Nour, 2020; Yan,

2020). This leads to the third reason for selecting OSGs as sources of information: continuous peer support. The OSG peers in this study not only attracted and encouraged new members by sharing their successful experiences, but they also provided support that was available 24/7, which enabled them to overcome different barriers and engage with and focus on the self-management of the condition. The two studies in Chapters 4 and 5 showed various types of support exchanged in the OSGs that influenced participants to become engaged in these communities as illustrated in Figure 6.4.



**Figure 6.4 Types of support found in OSGs**

As Figure 6.4 shows, the support reported in the two previous chapters can be categorised into four main types of social support behaviours as illustrated by House (1981, 1987):

- Informational support: the provision of guidance, recommendations and information that an individual needs to solve a problem. The findings in the two previous chapters clearly show that OSGs are used as a source to obtain basic information about the



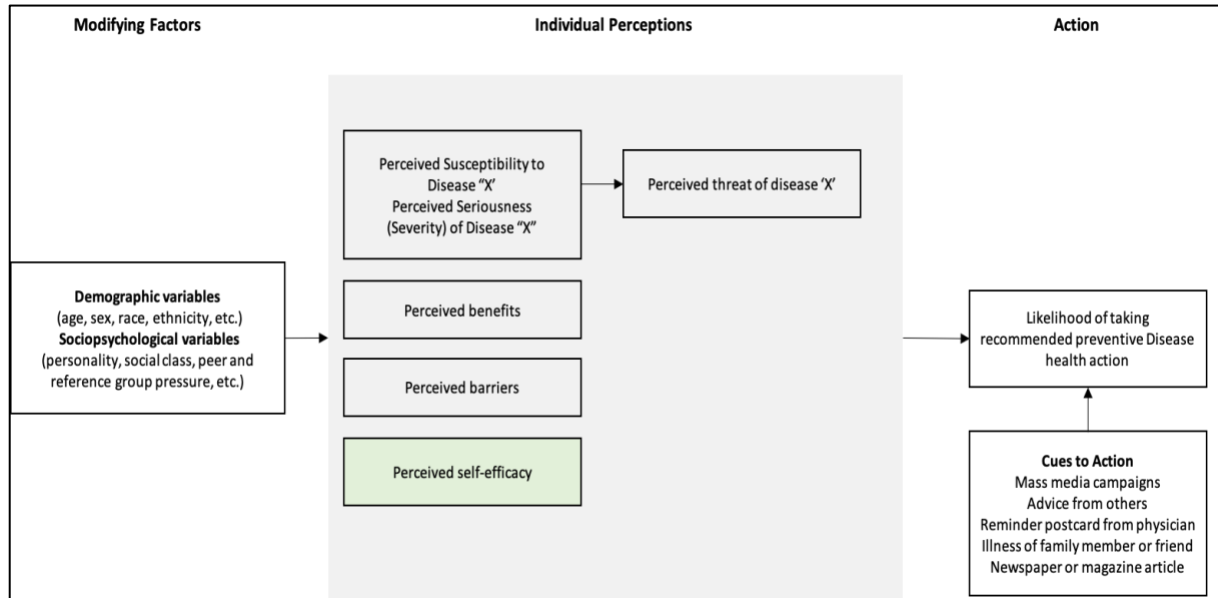
condition, treatment approaches and advice that arose from members' personal experiences.

- Instrumental support: includes offering practical/ tangible support that can be translated directly into action. Practical advice, such as meal recipes, were exchanged regularly between OSG members as the results of both studies (Chapters 4 and 5) showed.
- Appraisal support: the exchange of information that is helpful for self-assessment, including constructive feedback and affirmation. The findings show that appraisal support facilitated the implementation of the above two types of support through continuous constructive feedback. The three previous types of support have been largely described in the findings chapters (e.g. in Sections 4.3.2.1, 4.3.2.4.1, 5.3.2.3.1 and 5.3.2.1.3).
- Emotional support: the provision of love, empathy, kindness, trust, friendship and encouragement among others. This type of support was a major factor for many participants (e.g. Sections 4.3.2.5.1 and 4.3.2.5.3) as it helped them to overcome various barriers and difficult situations (as explained in Section 4.3.2.1.2 for instance) and encouraged them to stay motivated (Section 5.3.2.3.1).

These types of support might intersect and influence each other and do not operate in isolation (Moeini et al., 2020). For example, the provision of emotional support might increase the provision of instrumental support as well (Morelli et al., 2015).

Several researchers (e.g. Lee et al., 2017; Rad et al., 2013) have reported that social support is crucial for diabetes self-management to overcome barriers and achieve desirable health outcomes. In particular, social support plays an important role for people with T2D as it

reinforces an individual's self-efficacy to improve medical adherence and glycaemic control (Shao et al., 2017). This might explain the introduction of self-efficacy by Rosenstock et al. (1988) as a separate new construct in a later version of the HBM (Figure 6.5).



**Figure 6.5 The later version of the Health Belief Model that included "self-efficacy" as a separate construct. Adapted from Champion and Skinner (2008)**

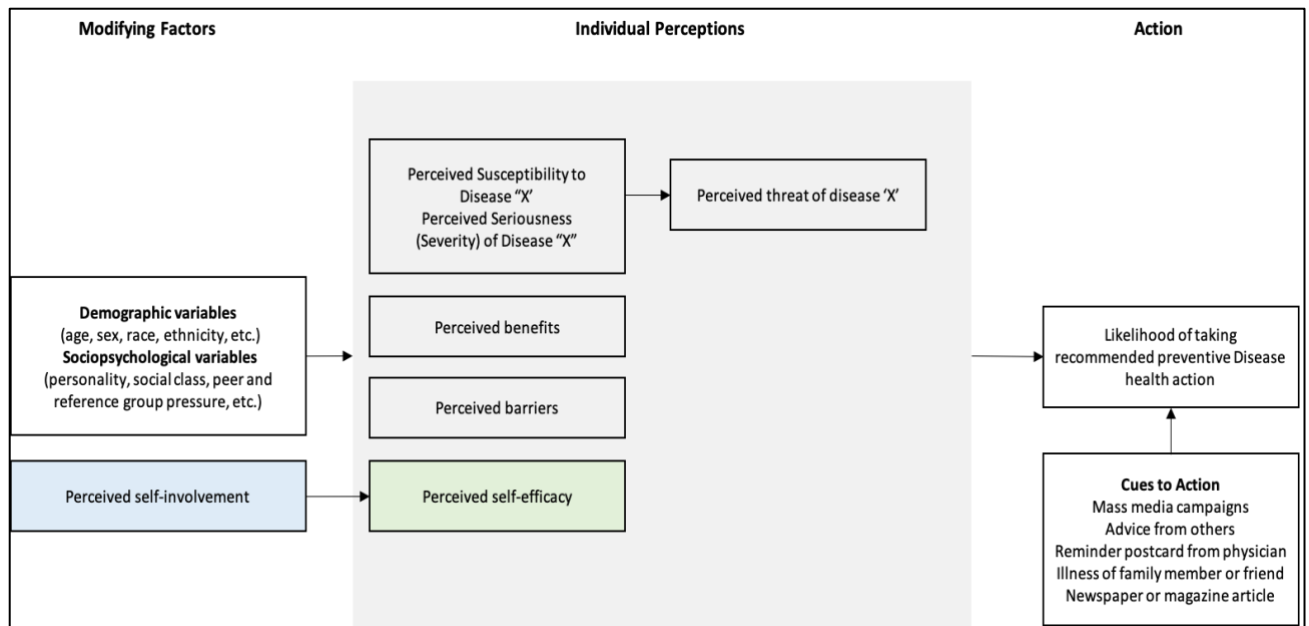
Champion and Skinner (2008) explained that self-efficacy was especially important for long-term health behavioural changes such as the ones involved in chronic diseases. This includes T2D, as it is not a static condition and people with the condition face various factors related to emotions, disease management and adaptability to the changes caused by the disease that make self-efficacy essential to successful control of T2D. While the perceived susceptibility and severity explain how individuals are threatened by their current unhealthy behaviour and the perceived benefit explains the advantages of performing the recommended behaviour, the perceived self-efficacy shows the capability (having the required knowledge and ability) of individuals to perform the change. This was supported by other theories (e.g. Social Cognitive Theory, or SCT) that positions self-efficacy as the central determinant of a behaviour (LaMorte, 2016). Regarding long-term conditions, having sufficient confidence in

one's capability towards making a behavioural change is essential, because it requires a long-term commitment. The current study supports the growing body of literature, for example Lachman et al. (2018) and Dorling et al. (2019), that highlights the importance of including self-efficacy as a main component in the initiation and maintenance of new health behaviour(s). Increased social support can enhance self-efficacy and, as a result, the individual's sense of empowerment and control (Antonucci, 2001; Chen & Feeley, 2012, 2013; Gerstorf et al., 2011; Kouvonen et al., 2012). The results of the two studies in the previous chapters show that the four types of social support exchanged in the OSGs can enhance an individual's self-efficacy. Informational, instrumental and appraisal support can be clearly seen through the instructions/information, experiences and constructive feedback exchanged between OSG members that enhance members' knowledge and skills. The benefit of emotional support might not be as obvious as the three previous types of support.

However, the findings of this study highlight that emotional support is as important as the other types of support. It provides continuous reinforcement to the perceived abilities of members that might fade over time. For example, Sarah and Jessica in Section 5.3.2.2.1 used the OSG over a long period of time, even for the purpose of satisfying their informational needs to obtain daily encouragement and support to keep them focused on maintaining their healthy behaviour. This support reinforced their efficacy so as to achieve and maintain the desirable behaviour. The current study therefore shows the importance of self-efficacy in initiating and maintaining a new health behaviour. Furthermore, this supports its inclusion as a separate construct within the HBM. However, it is essential to note the social, economic and educational background of the members and participants of the present study. The majority of the participants were White, middle-aged people with a high level of education (Table 5.3). It is possible that individuals from this background might already have a higher

sense of empowerment than other minorities. The latter were also reported to have an increased risk of T2D. Whicher et al. (2020), for example, reported that 12.5 million people in the UK were at an increased risk of developing T2D. In particular, individuals from South Asian and African-Caribbean backgrounds in the UK were found to be two to four times likely to develop T2D than White European (Ntuk et al., 2014). Compared to White populations, other ethnic minority populations in the UK were also reported to have a greater gap in knowledge concerning diabetes, physical activities, diet and challenges in changing health behaviours (Patel et al., 2017). The relationship between people's background and its role in influencing their sense of empowerment would merit further examination.

This study also showed how OSGs encouraged their members to be active and involved in their care. Section 4.3.2.2.1, for example, explained how members changed their perception about their role in diabetes management after engaging in OSGs. Various members thought that the only way to manage diabetes was through taking medications without making behavioural changes. The online community showed them how other members were active and involved in the management of their condition, and this encouraged them to do the same. Increased self-involvement in one's care is linked to better self-efficacy (Janssen et al., 2016), which contributes to achieving better health outcomes (Zachariae et al., 2003). This might also suggest the inclusion of self-involvement in health care as an activation construct to the self-efficacy in the HBM (Figure 6.6).



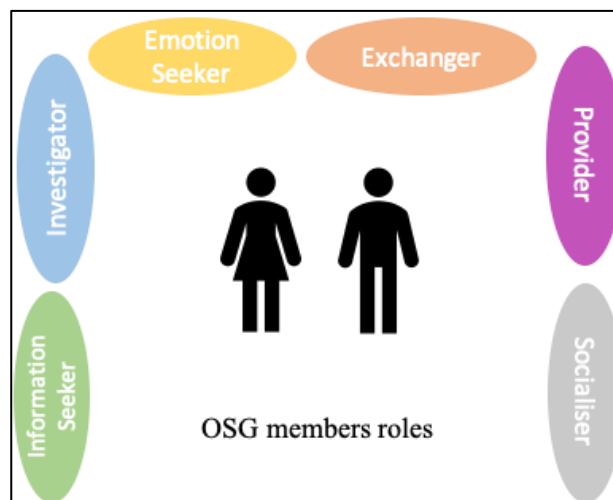
**Figure 6.6 Inclusion of the “perceived self-involvement” in the Health Belief Model which might explain how the "self-efficacy" is activated and influenced**

As Figure 6.6 sets out, an individual’s perceived involvement in their care can influence their efficacy to perform the recommended health action. In particular, the results of this study show that an individual’s perceived involvement can be influenced by various factors. First, observing how others with the same health condition are managing the condition puts them in comparison with their peers. Second, OSG members widely engaged in discussions aimed at persuading other members to play an active role in their care and to try different treatment plans. These discussions always highlighted the fact that the condition is the individual’s responsibility and they have to be engaged with it. Third, emotional stability was one of the main factors that affected individuals’ involvement in their care. Individuals go through ups and downs while managing their condition, which might result, in some cases, in experiencing negative emotions (e.g., anxiety) that disconnect them from their involvement in their care. Finally, observing their achievements kept various participants involved and focused on their care. These four factors identified by the current study agree with Bandura's (1986) factors of enhancing self-efficacy. Bandura explained that self-efficacy was

influenced mainly by four factors: self-performance accomplishment; peer experience; verbal persuasion; and physiological state. The current study suggests that these four factors form the perceived self-involvement that can directly influence self-efficacy.

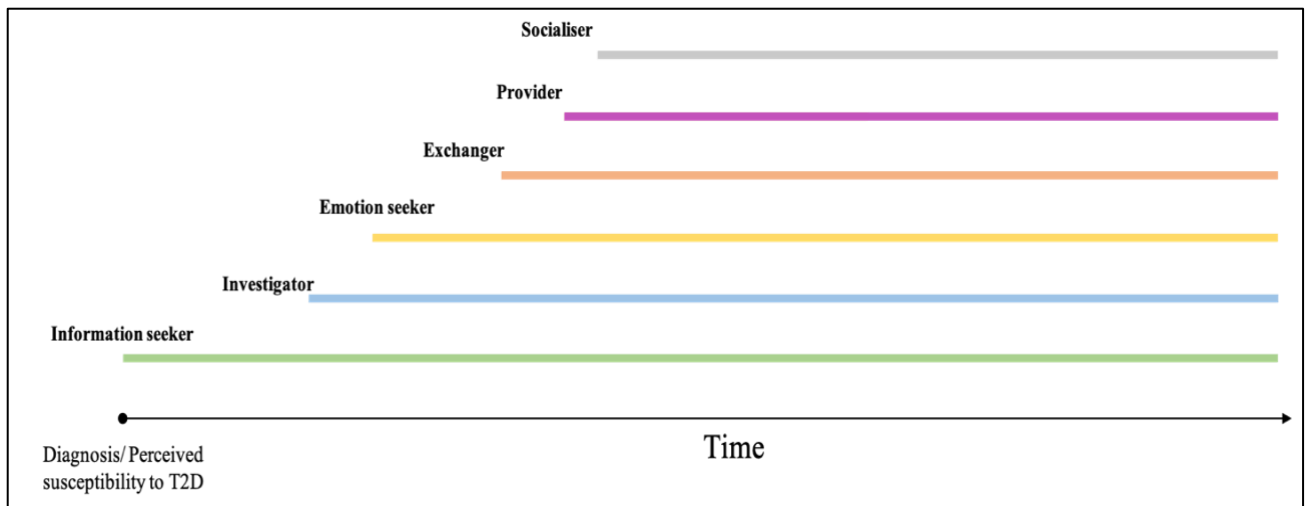
### 6.3 Online behaviour of OSG members

The findings of the current study show that OSG members play different roles in the community at different stages. Figure 6.7 below summarises the various roles found in the previous chapters.



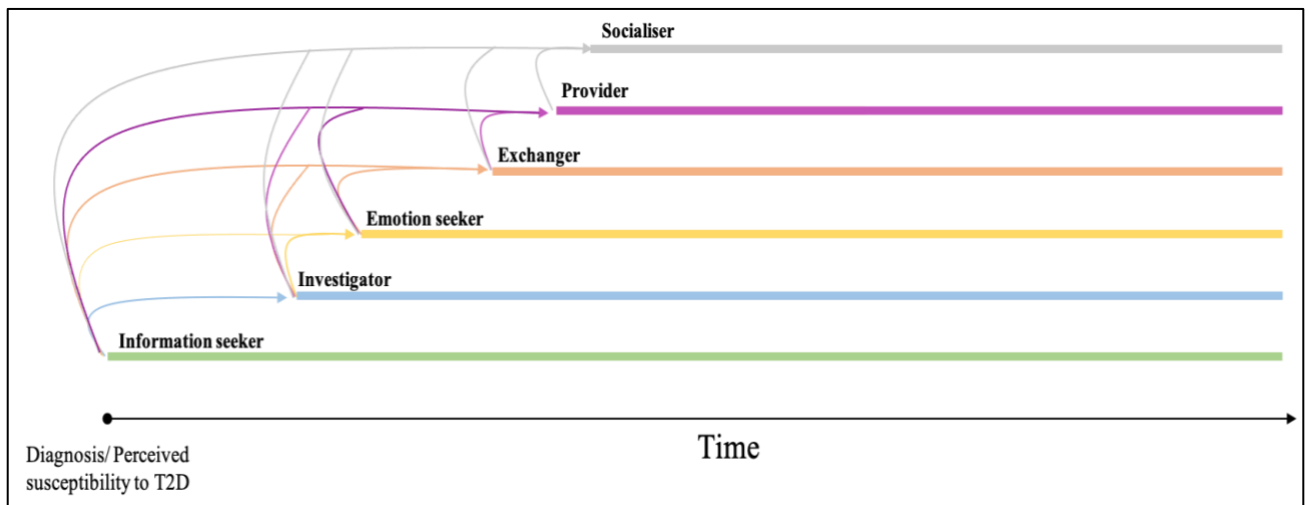
**Figure 6.7 Various roles of OSG members identified in the study**

Members appear to go through various modes in how they use OSGs. While not all members experience all of the identified roles, many of them go through various roles at different stages of using the OSG. However, the sequence of the roles differs from member to member and Figure 6.8 shows the most common sequence observed in many of the participants in this study. Whilst the majority of members started in the OSGs as information seekers, they might (or not) perform the other roles.



**Figure 6.8 Sequence of occurrence of various roles of OSG members identified in the current study**

As the discussion below will explain, members varied in the roles they performed in the OSGs. Members might transition from one role to another sequentially, skip role/s or remain in the same role as Figure 6.9 explains.



**Figure 6.9 Transition among roles might occur in consecutive or non-consecutive order**

The following sections explain the characteristics of each role.



### ***6.3.1 Information seeker***

As mentioned in Section 6.2.1, various factors created an information need for OSG members and participants in both studies that led them to seek information. When they first arrived at an OSG, they looked for information to help them understand and manage their condition and achieve positive health outcomes. This is the first and primary reason for most participants joining the OSGs. Information seekers either browsed the OSGs to read the information without posting (i.e. lurk) and/or posted their questions directly to the community. Various participants explained that they spent some time before posting for the first time to understand the interaction in the community and not to sound odd. This activity/role is found to be recurrent and the fulfilment of an information need might create a further information needs as explained by Wilson (1981). For example, various participants had information needs regarding diet options. They sought information in OSGs and, after investigation, they found that a low carbohydrates diet was useful for them. This created further information needs about the diet (e.g. how much carbohydrates they should have a day, recipes for that diet).

### ***6.3.2 Investigator***

After obtaining the information from the OSG and other sources, the participants would examine and validate it. Information from different sources might have been conflicting with each other (e.g., from the OSG, HCPs, and other websites). As such, they therefore engaged in different activities to determine which approach/information would be better for their health. For example, in Sections 4.3.2.3.1, 5.3.2.1.5 and 5.3.2.2.3, various members and participants explained that they applied the information they sought gradually alongside continuous self-monitoring of blood glucose levels to see how it affected their health. Some participants searched about the information they found in the OSG and had different

mechanisms to verify it (as explained in Section 5.3.2.1.4). OSG members in this role might also post about their own experience to obtain constructive feedback from their peers.

### ***6.3.3 Emotion seeker***

Members varied in how they use OSGs to support them emotionally. While some did not see any purpose in exchanging emotional support, the majority perceived it as an essential factor to achieve their goals. They needed it at the beginning of their journey (i.e., after finding and validating the information) to support their preferences (e.g., in case of uncertainty). For others, such exchanged support encouraged them to maintain their health behaviour even when they reach a stable health status (e.g. Section 5.3.2.3.1). This suggests that this role was not present for some members, was needed at the beginning to help others to find the appropriate treatment approaches and, for some, this role was essential in the long-term to help them stay focused and engaged in managing the condition.

### ***6.3.4 Exchanger***

After applying various types of information, members might share their experiences with other members so that other members could also benefit from it or they themselves could share their own achievements and express their gratitude to the community. It is important to highlight that members in this role might still have investigated the right approach for themselves and not have reached a final belief/result. However, they formed some experiences that they could share with other members and exchange informational and emotional support with them.

### **6.3.5 Provider**

In this role, members knew the best approach for themselves, had positive health outcomes and had confidence that this approach was the right one for them. In this role, they provided support to other members in the OSG. Some members engaged in wider activities, becoming activists and encouraging others to do so (e.g. through Patient Participation Groups) to demand the information/support for people with T2D to be changed/improved (as explained in Section 5.4.4). The study shows that the reciprocity behaviour observed in the study was not limited to other OSG members but also to the wider population of people with T2D, irrespective of whether they were online or offline. This will be discussed in further detail in Section 6.4.2. De Simoni et al. (2020) named users in this role as *superusers* and reported that they formed 1% of UK-wide OSG population. Users in this role are highly engaged and influential in the community and perform tasks similar to those of the moderators (Coulson & Shaw, 2013).

### **6.3.6 Socialiser**

When members joined the OSGs to satisfy their needs, they built connections and interpersonal relationships with other members, and the community as whole. After their needs were fulfilled and they were in a position in which they could depend entirely on themselves, they kept accessing and using the OSG to stay connected with their peers and share their daily life updates. They explained that their time and communications with other members in the OSG form an essential part of their social life. Therefore, they kept using the OSG to maintain these relationships (e.g. Section 5.3.2.2.1).

Table 6.1 shows an example of the different roles observed in the study in Chapter 4.

**Table 6.1 Roles observed for some members in the analysis of the posts study**







Roles	Participant				
Information Seeker 	1- Riley <sup>4</sup>	1-Katelyn	2- Phoebe	1- Alexis	2- Isabella
Investigator 	1- Mary	1- Bryan	1- Jacqueline	1- Katelyn	1- Riley
Emotion seeker 	1- Abigail	2- Phoebe	2- Sofia	2- Imogen	2- Tracy
Exchanger 	2- Logan	1- Mary	2- Evie	1- Henry	2-Jacob
Provider 	1- Alexis	1- John	2- Logan	1- Sean	1-Katelyn
Socialiser 	<i>Not identified</i>				

Table 6.1 reveals that different members had different roles in the OSG. While most roles were observed in the analysis of the posts study, the socialiser role was not identified. This might have been because members did not express their reasons for using the OSG after satisfying their needs. However, this was answered by a direct discussion with the participants in the Interview Study as Table 6.2 shows.

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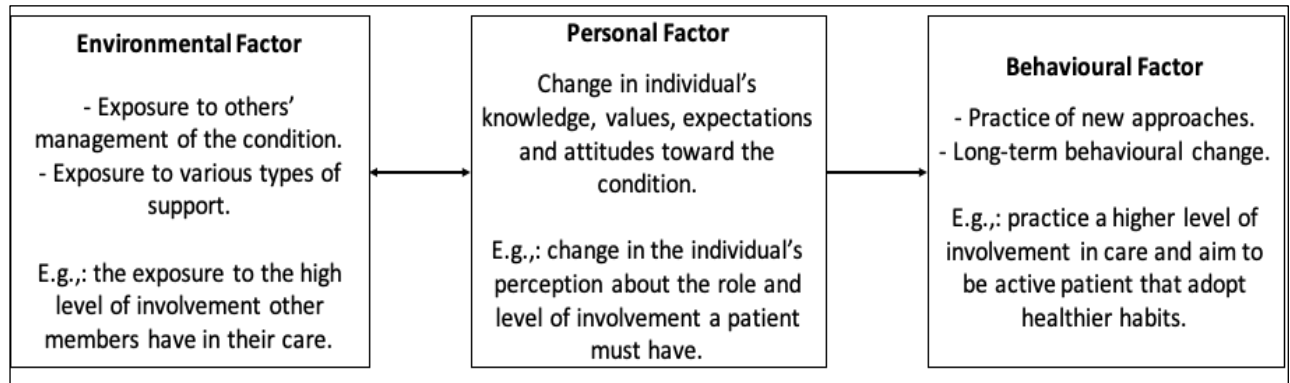
<sup>4</sup> The Number prior the name of OSG members represents the OSG they belong to as explained in Section 4.2.4.

**Table 6.2 Roles observed for participants in the interview study**

Participant	Roles identified					
	Information Seeker	Investigator	Emotion seeker	Exchanger	Provider	Socialiser
Harry, Sally	●	●				
Oscar	●	●				●
Elizabeth, Lucas	●	●		●		
Daisy	●	●	●			
Andrew, Isabelle	●	●		●	●	
Jessica	●	●	●	●		
Mary, James	●	●		●	●	●
Sarah, Sophia, Catherine	●	●	●	●	●	
John, Emily, Alice	●	●	●	●	●	●

As Tables 6.1 and 6.2 show, members and participants varied in how they used the OSG. While most of them went through information seeking and investigation of the right approach as basic roles, they varied in whether or not they undertook the rest of the roles. Members who used the OSGs as a problem-solving platform limited their use to the first two roles at most. While they were in these two roles, they might have posted (e.g., asked direct questions) or acquired information to explore the right method for themselves. Their activities were limited to only benefitting themselves without sharing their experience to support others. These two activities might have been performed in complete silence (e.g., Oscar from the interview study did not post in the community) or limited their engagement to get feedback from others (e.g. Harry and Sally). This did not limit them in terms of gaining

the community's values such as the importance of patient involvement and self-efficacy. This can be explained by Bandura's (1986) SCT that the observation of others can influence an individual's personal values and behaviours (as shown in Figure 6.10).



**Figure 6.10 conceptual framework based on The Social Cognitive Theory (Bandura, 1986a)**

The influence that OSGs had on lurkers illustrates that, although active engagement in online communities might result in positive outcomes for individuals, lurking also had positive impacts on OSG users. SCT explains that any change in an individual's environment influences their personality and behaviour. The OSG may serve here as an environment that influences users' personalities and behaviours. This suggests that the impact of OSGs might not be limited to their enrolled members but also to non-registered users: van Mierlo (2014) claimed that these observers accounted for the majority (i.e. 90%) of OSG users.

Interestingly, the silent engagement (i.e., lurking) within the OSG might also build a social unidirectional connection between the user and the community without the user ever posting in the community. For example, in the interview study, Oscar felt that he belonged to the community and kept accessing it for a long time even after fulfilling his informational needs; however, the other members of the community were not aware of his presence. One of the reported explanations by the participants for not posting in the community was that of

avoiding pointless arguments with other members. Further research needs to be carried out to investigate the impact of silent engagement with OSGs on users.

Other members and participants involved in more roles (e.g. *exchangers* and *providers*) enriched the content of the community. These members were the main contributors to the knowledge and values in the community. This included improving the human, social, information, reputational and learning capital of the community (Wenger et al., 2011). In particular, users that turned out to be *providers* were reported to be a key component of the success of OSGs and contributed to the vast majority of the content (Van Mierlo, 2014). Weibull (1985) illustrated that people's use of media is influenced by their needs, motivations, expectations, sociological and psychological structures as well as their past experiences with the media. Therefore, the members and participants in the current study showed different uses of the OSGs.

The Uses and Gratifications Theory (UGT) argues that people use mass media to satisfy their knowledge, emotional, social, personal and/or entertainment needs (McQuail, 1987). The roles identified in the current study correspond with media uses identified by the UGT (Table 6.3). The ticks in the table below showcase the intersections of the roles (from the present study) with the fulfilled corresponding needs (reported by the UGT).

**Table 6.3 Intersection of media uses in UGT and the roles identified in this study**

Roles identified in the current study	Cognitive needs	Affective needs	Social integrative needs	Personal Identity	Entertainment
Information seeker	✓				
Investigator	✓				
Emotion seeker		✓			
Exchanger	✓		✓		
Provider		✓	✓	✓	
Socialiser		✓	✓	✓	✓

OSG users accessed and used OSGs to satisfy their cognitive and affective needs, and these formed the majority of the uses observed in this study. Other members used the communities to satisfy their needs for social interaction and to gain a sense of belonging to the community that resulted in an increased frequency of using the medium (Joinson, 2008; Muntinga et al., 2011). The UGT posits that some people use the media to reinforce different values of their identity such as self-esteem and civic mindedness (Calder et al., 2009). Finally, some users kept using the community to entertain themselves (e.g., as explained in Section 5.3.2.2.1). This use was usually linked with known entertainment platforms (e.g., Radio and television programmes) (Katz et al., 1973) and online platforms (e.g., Facebook and Twitter) (Cheung et al., 2011; Dolan et al., 2016). Interestingly, some participants in the current study reported that they continued using the diabetes OSGs to entertain themselves. This study shows that each role might satisfy one or more needs.



### **6.3.7 Summary**

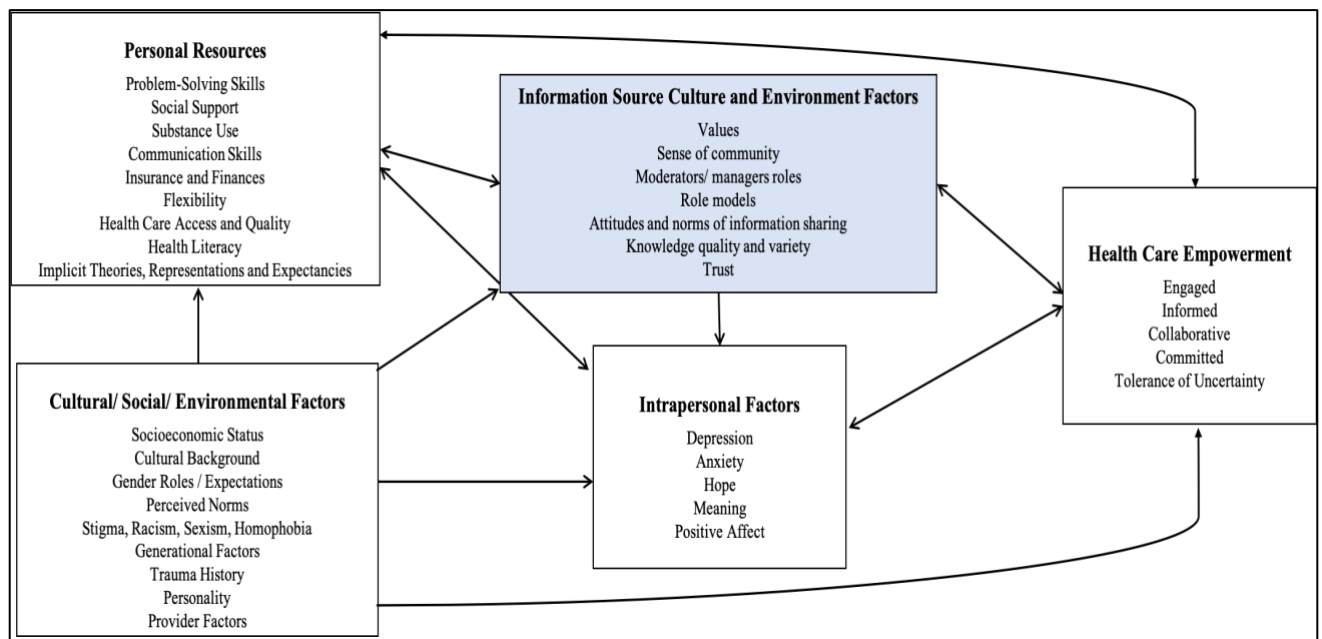
To summarise, this study introduced various roles that OSG users performed in the community. Each role was found to satisfy one or more need(s) identified in UGT. Further, this study shows that the majority of users arrived at the community to seek information and explore various approaches to manage the condition. However, they differed in terms of how they subsequently used the community. Users who limited their use to information seeking and investigating the right approach to manage the condition successfully gained the benefit from the community by observing and learning from their peers. However, the benefit of their use was limited to themselves. The study revealed that silent engagement in OSG might have as beneficial an impact on, and attachment to, the community as active engagement. Members who performed further roles in the community evidenced impact on themselves, as well as on other peers in the community. This highlights the importance of the recruitment and retention of such users to ensure the long-term success of the community. In particular, OSG moderators are recommended to encourage *exchangers* to become *providers* in the community while maintaining the latter.

## 6.4 Factors influencing patient empowerment

### 6.4.1 Introduction

This section aims to discuss different factors identified in the present study and how they influenced the empowerment of the participants. The discussion will employ the Health Care Empowerment Model (HCE) to understand how the factors interacted and how the study contributes to the model as well as to our understanding of health care empowerment in the context of people with T2D using OSG in the UK.

Figure 6.11 below shows the HCE model factors and elements and the factors developed from the findings in the present study: *Information Source Culture and Environment Factors*. The information source here refers to any source that provides information such as OSGs and HCPs. Many of these factors apply to all sources, but not all (e.g. the *sense of community* can help understand the difference between OSGs but might not be applied to HCPs).



**Figure 6.11 The introduction of Information Source Culture and Environment Factors identified by the current study in relation to Johnson's (2011) HCE Model**

The figure above shows the HCE Model as introduced by Johnson (2011) and presents a new set of factors (highlighted in blue) related to the source of information as identified by the present study. It explains how the factors influence others and how that results in affecting the explained empowerment elements.

Table 6.4 below synthesises the factors identified in the current study and how they influenced others, in relation to the relevant sections of the results and discussion chapters. The table categorises the elements based on which factor of the HCE model they belong to, provides examples from the current study of the influencing factor and then shows how that factor affected others. It shows the key effects of the factors related to the information source culture and environment.

**Table 6.4 Examples of the identified HCE-model factors by the current study and how they affected others**

Influencing factors on empowerment	Factor	Example of the factor identified in the present study	Section in which the factor was presented/ discussed	Example of empowerment elements and other factors influenced
Information source culture and environment factors	Values	Dis/encouragement of active patient involvement in care.	4.3.2.2.1, 4.3.2.2.2, 4.4.5, 4.4.6, 5.3.2.2.1, 5.3.2.3.3, 5.4.5, 6.2.2	Being engaged, informed, collaborated and committed. Problem-solving skills, health literacy, social support, hope and anxiety.
		Support of experience-based over evidence-based information.	4.3.2.3, 4.4.2, 4.4.4, 4.4.7, 5.3.2.1.5, 5.3.2.3.3, 5.4.3	Being informed, doctor-patient relationship, problem-solving skills and health literacy.
		Emphasis and adoption of personalised treatment approaches.	4.3.2.1.1, 4.4.8, 5.3.2.2.2	Being engaged, informed, collaborated and committed. Problem-solving skills, health literacy, social support and flexibility.
	Sense of community	The culture created in an online community contributed to attraction of new members to join and continuously use the OSGs. It also contributed to how members would use the community and perform different roles.	4.3.2.1, 4.4.3, 5.4.3.2, 5.4.4, 6.2.2	Being engaged, informed, collaborated, committed and tolerated with uncertainty. Various intrapersonal factors (e.g. increased hope and decreased depression and anxiety due to be part of the community).
	Moderator and manager roles	Moderators and managers of the information source were key in the control and monitoring of creating the culture environment of the resource as well as the seriousness/ flexibility of the application of guidelines.	5.4.3	Being engaged, informed, collaborated and committed. Various positive and negative intrapersonal factors (e.g. hope and depression). Problem-solving and communication skills.
	Role models	The observation of other individuals that act as <i>providers</i> in the community spread what is normal practice and what is not.		

Contextual factors	Attitudes and norms of information sharing	<p>The support of freedom or limitation of information sharing. For instance, when Isabelle (form the Interview Study) shared her experience with challenging the health care system, many members of the community (including moderators) were against the sharing of such experience. However, this behaviour was encouraged in other OSGs such as what 2-Isla and 1- Mackenzie from the Analysis of the Posts Study reported.</p> <p>Another example would be Mary (form the Interview Study) was discouraged by diabetes educators to share her experience with self-testing with others during an official education course.</p>	5.3.2.1.2, 5.3.2.2.1	Being engaged, informed, collaborated, committed and tolerated with uncertainty. Positive intrapersonal affect, problem-solving and communication skills, social support, flexibility access to better health care quality and health literacy.
	Knowledge quality and variety	The quality and variety of the knowledge exchange/ presented in a source was key criteria to select the source.	4.3.2.2.1, 4.4.7, 5.3.2.1.4	Health literacy, doctor-patient relationship and various intrapersonal factors.
	Trust	Trust placed on information source was seen to be highly critical to how individual select and use the source as well as utilise the information obtained from it.	4.3.2.1.1, 4.3.2.1.2, 4.3.2.2.1, 4.3.2.3.1, 4.3.2.3.2, 4.4.7, 5.3.2.1.4, 5.4.3	
	Personality	Challenging care provider recommendations and following OSG peer's advice.	4.3.2.2.1, 4.4.5, 5.3.2.2.2, 5.3.2.2.4	Being engaged, informed, collaborated, committed and tolerated with uncertainty. Access to wider social support network (i.e. OSGs), demand more health care care service and rights and improved health literacy.
		Sense of reciprocity and personality influenced the engagement with, and roles performed in OSGs.	5.3.2.2.4, 5.4.4, 6.3	

Personal resources	Perceived norms	Individuals' choices were perceived as questioning the knowledge of HCPs and the system.	4.3.2.2.2, 5.3.2.2.1, 5.4.5	Being engaged, informed, collaborated and committed. Health literacy and care quality, problem-solving and communication skills, doctor-patient relationship and various intrapersonal factors.
	Provider factors	Background, training and culture of HCPs and educators influenced the quality and variety of information provided and support to individual's choices.		
	Social support	Support (or lack of support) received from the individual's social circle.	4.3.2.2.3, 5.4.5, 6.2.2	Being engaged, collaborated, committed and tolerated with uncertainty.
	Health Literacy	Previous experiences with other condition or with T2D created an expected health experience and outcomes.	5.3.2.1.1	Being engaged, informed, collaborated, committed and tolerated with uncertainty. Preferred (trusted) information sources and various intrapersonal factors.
	Problem-solving skills	The ability of individuals to overcome T2D-control challenges such as unknown reason for increased blood-sugar levels.	4.3.2.1, 5.3.2.1.5, 5.3.2.2.3	Being engaged, collaborated and committed. Overcome various intrapersonal factors such as fear and depression.
	Communication skills	The desire to get involved in an online community that had a huge number of members and controversial discussions. For example, Lucas from the Interview Study disengage with the OSGs because of getting in tensional discussions with other members. Communication and convincing HCPs about their treatment choices.	4.3.2.2.1, 4.3.2.4.2, 5.3.2.2.4, 5.3.2.3.2	Sense of community, various intrapersonal factors.
		Communication with other parties such as the CCG to get the care that they were eligible for.		Being engaged, collaborated and committed. Health care quality, various intrapersonal factors and doctor-patient relationship.

Intrapersonal factors	Depression and anxiety	As a result of dealing with different waves, relapses and side effects of the condition. For example, 2- Imogen from the Analysis of the Posts Study was going through serious depression as a result of dealing with the condition and its side effects.	4.3.2.1.2, 5.3.2.3.1, 5.4.2	Being engaged, collaborated and committed. Problem-solving and communication skills.
	Hope	Belonging to a community where other acted as role models whom success stories with the condition provided them with the sense that they could achieve better health outcomes.		Being engaged, informed, collaborated, committed and tolerated with uncertainty. Problem-solving and communication skills, social support, health literacy and flexibility.
	Beliefs and attitudes	Individuals' perception that T2D is their condition and they have to play an active role with taking care of it.	4.3.2.2.1, 4.3.2.3, 5.3.2.2.2	
	Determination and will	The use of OSGs every day and logging activities maintained individuals' determination and will to achieve their goals in the long term.	4.4.3, 5.3.2.3.1	

#### ***6.4.2 Information Source Culture and Environment Factors***

This section aims to discuss the culture and environment of the two information sources identified in the present study (i.e. through official channels such as HCPs and via OSGs) and how they influenced the empowerment status of the participants. Widén and Steinerová (2019) explained that information culture can be seen in the values, attitudes, norms and practices in the context where the information is exchanged and valued.

First, the participants of the present study explained that they received official support via two main channels: meetings with their doctors/ diabetes nurses and/or attending the Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) programme. The DESMOND is the official educational programme recommended by the National Institute for Health and Care Excellence (NICE) for people with T2D since 2008 (Chatterjee et al., 2018). The 6-hour, in-person programme aims to provide people at risk and newly diagnosed with T2D with the required knowledge and skills that empower them to successfully manage and control their diabetes (Carey et al., 2012; Department of Health, 2001a; Hex et al., 2012; Odgers-Jewell et al., 2017). Various studies (e.g., Chatterjee et al., 2018, Khunti et al., 2012) have reported that the programme demonstrated its effectiveness in improving the self-management skills that resulted in a significant reduction in HbA1c levels for its attendees. However, there are no data on the psychological and emotional effects of the programme on its attendees: Khunti et al. (2012) reported that the programme had no bearing on biomedical and lifestyle outcomes and Chatterjee et al. (2018) reported that there was limited data on these outcomes.

The results of the current study suggest that, although the programme was controversial among the members and participants of the present study, it had positive and negative sides.



The programme provided the newly-diagnosed participants with basic and useful information about the condition, its causes and how to deal with it. However, many participants and members perceived the information provided in the programme and by the HCPs as limited. They explained that such information assumed that all people with T2D would have the same reaction to the condition and had to follow similar treatment approaches. Alternative treatment approaches, such as low-carbohydrate diets, were not introduced or allowed to be discussed as reported by various participants and members. The lack of freedom of information and discussion created tension between attendees (especially those who had knowledge of alternative approaches prior to attending the programme) and the programme presenters. As a result, the programme was perceived as less effective and led attendees to leave the programme or discourage others from attending it, as was explained in Sections 4.4.4, 4.4.8 and 5.3.2.1.2.

The lack of information variety and freedom provided by HCPs and DESMOND educators and the use of a one-size-fits-all approach contradicts what the NHS proposed towards diabetes care and education. NHS England (2014) stated that the health care system would “empower patients with information to support their choices about their own health and care” (p. 7). This is in line with the growing body of literature supporting personalised care towards T2D. Boels (2019) explained that diabetes care is expected to be personalised in the future and reported that people with T2D who followed a personalised treatment plan showed better results in comparison with those who followed a one-size-fits-all approach. This was realised by the NHS as its 2015-2020 plan stated that “it is a future that empowers patients to take much more control over their own care and treatment” (NHS England, 2014b, p. 7). However, the majority of the participants and members in the current study reported a lack of variety of information and support for their choices. This caused them to rely on, and seek

information and support from, other sources, and so created tension between them and HCPs/ DESMOND educators and led them to encourage others to do the same. Some of them were also active and tried to change the information and support provided to people with T2D (as explained earlier in Section 6.3.5).

Part of the problem was that the information and approaches causing the tension was also controversial among scholars (such as the LCHF diet). However, people who followed them argued that the approaches were effective for them and they would prefer experience-based medicine rather than evidence-based medicine. Recently, the low-calorie diet was introduced to be tested in the NHS 10-year Long Term Plan (NHS, 2019) after proving its effectiveness to achieve non-diabetic glucose levels for people with T2D (Lean et al., 2018). This diet for example caused tension between HCPs and members and participants that wanted to use it to manage their T2D. This shows the importance of introducing various information and treatment options to patients, providing them with information about which is evidence-based, and which is experience-based, providing the medical advice appropriate to the individual and supporting their choice, even if it is not the recommended one. This would provide people with T2D the awareness about the available approaches, the freedom to choose, the opportunity to discuss and follow the approach that works for them without being worried about it affecting their relationship with their care providers or having limited medical support as a result of not following the care provider's recommended approach. As a result, this would contribute to improving their sense of empowerment.

OSGs that only repeated and followed the information provided by HCPs were less favoured by the participants. OSGs that provided a wide range of information and treatment approaches, had encouraging culture into patients' active involvement in care and

personalised treatment were selected as an information source. This not only enhanced individuals' engagement with self-care and, as a result, their sense of empowerment, but also contributed to encouraging them to change the position and care provided to people with T2D as a social group by advocating their demands. These social activities were referred to by Hur (2006) as *collective (or interactional) empowerment* and defined as the processes by which people join together to overcome shared challenges and attain social change for their disadvantaged position. Zimmerman's (1995) empowerment theory suggests that empowerment consists of at least two dimensions: individual and collective (interactional) empowerment. The present study suggests that, in order for individuals to be active in collective empowerment, they first need to achieve self-empowerment. For example, participants that moved to be *providers* in the community first reported an enhanced self-sense of empowerment. The current study agrees with Liu et al. (2017), who reported that the activities of the OSGs influenced the self-concepts (i.e., their identity) of individuals to be similar to the ones of community. This, as a result, leads to a collective engagement of individuals in the community. The present study adds that this collective engagement influences an individual's participatory behaviour not only to the OSG community but in a wider context (e.g., the engagement in the Patient Participation Groups). This, as a result, enhances the overall collective empowerment of the online and offline community. Atanasova & Petrič (2019) reported that collective empowerment in health OSGs consists of two main components: the knowledge of the OSG and the mobilisation for collective actions. These are captured by the *values, attitudes and norms of information sharing and knowledge quality and variety* introduced by the *information source culture and environment factors* in the current study as explained in Table 6.4. Widén and Steinerová (2019) explained that although individuals might influence the culture of the information context, the latter has a stronger effect on information behaviour of individuals. This might explain the differences

between various OSGs. OSG managers have the potential to build these values and norms within the community. Members, however, might find introducing such values and norms to a community that do not support them challenging. As a result, they might exit from that community and/or shift to another one (as explained in Section 5.3.2.3.3).

However, the subjectivity of the reported sense of empowerment gained from using the OSGs in this study should be noted. It might be possible that, when members and participants in both studies reported that they gained a sense of empowerment after using OSGs, this reflects their own, time-specific feelings. For example, they might have used information shared via the OSGs that led to a negative consequence in the long term. Further studies, therefore, are needed to examine the accuracy and validity of the information exchanged in the OSGs.

The factors presented by the present study are critical elements in how the participants behaved in the communities and contributed to the empowerment of the community. These factors add to the growing body of literature on understanding the factors that influence individual and collective empowerment in different sources of information, especially OSGs and care providers.

#### ***6.4.3 Contextual factors***

Johnson (2011) reported culture, social and environment factors of individuals were found to be the widest category of factors that influence health care empowerment. The present study found a number of contextual factors that influenced individuals' empowerment. First, an individual's personality was found to be a major influencer in how individuals navigate through, and engage in, different information sources and how they would utilise the information obtained. For example, various participants explained that their curiosity led

them to seek information from multiple sources as soon as they perceived their susceptibility to the condition. Others, however, relied mainly on HCPs to provide information. Similarly, when they found alternative approaches to treat T2D, individuals differed in whether or not to follow such recommendations and how to challenge care providers if it was against their recommended advice. This attitude might have been influenced by the individual's previous experiences (e.g., with other health conditions and care providers). This agrees with Viwattanakulvanid and Kittisopee's (2017) findings that an individual's personality is a major factor affecting patient empowerment.

Personality was also found to be the main influencer on participants' engagement and role in the OSGs. For instance, some participants did not post immediately in the OSGs, because they did not have the courage or interest to write to thousands of online users. An individual's personality, especially their reciprocity behaviour, also affected how they performed different roles, as explained earlier in Section 6.3. The present study suggests that members' contribution to the knowledge in OSGs is influenced by their personality (e.g., their capacity for reciprocity behaviour and their self-confidence) as well as OSG-related factors (e.g., sense of community and moderators' roles). This concurs with Bernardi and Wu (2017), who reported that sense of community, self-confidence in one's knowledge and reciprocity behaviour were found to be key factors to OSG members' knowledge sharing. The current study suggests that a sense of community is not the only OSG-related factor influencing members' contribution to sharing knowledge. More OSG-related factors, explained in Section 6.4.2, such as OSG values, moderator roles and attitudes and norms of information sharing were all found to affect how members share knowledge with their peers in the OSGs.

Other contextual factors such as perceived norms and care providers were identified. They acted as facilitators or barriers to individual empowerment. The findings clearly explained

how HCPs varied in perceiving a patient's choice and how that influenced other factors, such as the patient-doctor relationship and a patient's engagement with care. As explained in Sections 4.4.4 and 5.4.5, participants' seeking information from various sources, including OSGs, introduced them to various treatment techniques that were not favoured by many care providers. On the other hand, participants who had HCPs who accepted having a partnership relationship in which the patient and HCP worked together to achieve better outcomes showed gratitude to their care providers who, they felt, respected their choices and enabled them to gain control over their health. The results of this study stress the critical influence of care provider-related factors, such as their acceptance of a patient's active participation in their care, on patient empowerment. The present study accords with Audrain-Pontevia and Menvielle's (2018) findings that OSGs have the potential to improve the patient-doctor relationship. OSGs, however, have also the potential to impair the relationship, depending on how HCPs perceive and react to the active participation of patients in care.

The results showed that active participation in care culture was widely present among the participants. This also includes questioning the knowledge of care providers and not following their recommendations. This is not common nor familiar in other geographical regions. For example, Matusitz and Spear (2015) reported that being active patients and questioning authorities, such as doctors, is not accepted by patients in some Asian cultures, such as in Pakistan, Japan and Thailand. The norm in such cultures is to respect authorities and, in these countries, this has more value than patient empowerment or involvement in care. The results of this study, however, suggest that the culture and norm between patients and health care professionals in the UK might mean that patient involvement in health care is more acceptable and encouraged. This also was reported by other researchers such as Goodwin et al. (2011). Although the results of the present study highly suggest this, further

quantitative research is needed to explore the norm and patient involvement culture for people with T2D in the UK.

#### ***6.4.4 Personal resources***

The results showed various elements related to participants' personal resources that influenced their sense of empowerment. Social support is a main element and participants varied in the amount of support they received from their social circle especially regarding following controversial treatment approaches. For example, various participants explained that their spouse did agree with them to go against what the HCP recommended. They reported that they used the positive experience of other OSG members as well as their own improvement to convince their partners about the treatment approach. Others, however, showed less interest in having their partners on their side. They explained that they would follow the approach regardless of whether others agreed with them or not. This suggests that, although social support network is usually perceived as a facilitator to better physical and mental health outcomes and patient empowerment (e.g. Alsubaie et al., 2019; Al-Dwaikat et al., 2020), it might also influence and alter patient decisions regarding their treatment. This might act as a hindrance to the utilisation of some helpful information obtained from OSGs or other sources.

Problem-solving and communication skills are other personal resource elements that were identified in this study. The engagement and information exchange with other OSG members clearly improved participants' T2D problem-solving skills which, as a result, enhanced their sense of empowerment and helped them overcome emotional challenges. For instance, participants learned to self-test their blood sugar levels before and after their meals, to determine whether their body had reacted positively or negatively to the food consumed. This

helped them to overcome the uncertainty of the effect of food on blood sugar levels. The results also showed that communication skills impacted on how participants engaged with their peers within the OSG and with their HCPs. Participants with better skills responded cautiously to potentially sensitive topics with their OSG peers and HCPs. This allowed them to maintain a stable relationship with their peers and care providers and avoid going into argumentative and stressful discussions.

#### ***6.4.5 Intrapersonal factors***

The psychological state had both a direct and an indirect effect on how the participants sought and used information, communicated with their OSG peers and HCPs and, as a result, on their sense of empowerment. The nature and instability of the condition and various influencing variables (e.g. medication, physical activities and food), unstable relationships with care providers and the discovery of conflicting information caused stress and negative emotions for many participants. Various participants reported that this, and the lack of psychological support provided to them, created an emotional challenge for them, as explained in the following quote:

*“I was absolutely horrified and I felt like I was abandoned immediately into an ocean ... they [the HCPs] gave [me] the most devastating news probably that I have ever had about me personally, health-wise. Then, they said: next patient, thank you very much! I was shocked, I was horrified! I was kind of like I am on a ship, ship sinks and now I am stuck in the water, sharks everywhere” (John-interview study)*

The feeling of being lost and having no emotional support was widely observed in the data, especially given that emotional and psychological support is offered to only 24% of people with diabetes (Diabetes UK, 2018). These stressful emotions influenced the patients’ engagement with, and commitment to, health care. However, the present study shows that the



engagement in communities where there are people with a similar health condition was found to be a powerful way to overcome such challenges, as John continued to explain:

*“I watched the shore and because I watched the shore these people [OSG members] came out and pick me up, drive me off, fade me, looked after me, educated me and I kind of thinking it was a small desert island community, for me it was a health crisis” (John- interview study)*

OSG peers did not only help in overcoming such negative emotions, but also assisted in building their hope to live normally with the condition and tolerate its uncertainty. The culture of the community created and reinforced some positive attitudes and values in its members, such as the importance of the patient’s active participation in care. As a result, this enhanced their sense of empowerment tremendously. The present study accords with the literature (e.g. Yao et al., 2015; Chen et al., 2019), which emphasised the importance of OSGs as a source of emotional supporter that directly affect patient self-care.

#### **6.4.6 Summary**

This section sought to better understand various factors affecting patient empowerment and the interaction between these factors. The Health Care Empowerment Model provided a useful framework to help understand the role of different elements to facilitate and hinder empowerment in health care. The findings of this research contribute to the existing knowledge about patient empowerment for people with T2D using OSGs in the UK. In particular, the study adds a new set of factors to the HCE model, which was found to have fundamental influence on patient empowerment. Information-source-related factors greatly differed between various sources as shown in this study and this set of factors added to the HCE model aims to draw attention to the importance of such elements in information sources. The current research also identified various contextual, personal resources and

intrapersonal factors that affected empowerment in different ways. Taken together, this section discussed and summarised the empowerment-influencing factors found in this study.

## **6.5 Theoretical development**

This section will discuss the theories and models presented in Chapter 2 and how they were used in the analysis. The section will also explain how this study helped improving our understanding of the studied phenomena.

First, the study aimed to investigate the role of OSGs in empowering people with T2D in the UK. The literature showed that the term patient empowerment was defined and interpreted differently by scholars (as explained in Sections 1.2.3, 2.3.4.4 and 2.7). There was a need, therefore, to define empowerment and adopt a definition or a model that explains the term in this study. The HCE was sought to provide a comprehensive understanding of empowerment, its components and influencing factors. As explained in Section 2.3.4.4, the model outlined that empowerment in health care consists of five main constructs: being informed, engaged, committed and collaborated and being able to deal with uncertainty. The model explained that empowerment in health is a state and process and is affected by various contextual and intrapersonal factors as well as many personal aspects. The model helped set up some of the research questions and collect and analyse the data (Section 3.5). It informed the researcher about what might influence empowerment and led him to pay attention to these issues. For example, tensional relationship with care providers, the use of health care services and patient's communication and problem-solving skills were outlined in the model as influencing factors on empowerment and were also found to be predominantly present in the data. The model also outlined that intrapersonal factors play a critical role in changing the

empowerment status of individuals. In the data collection and analysis, part of the attention was drawn to how the OSGs supported their members to maintain a good mental health and how that is linked to their sense of empowerment. The data clearly showed that many members and participants used the OSGs to support them socially and mentally (Section 2.2). The analysis also showed that this use of OSGs helped many people to improve their management skills of the condition, maintain a good health and overcome various challenges. This, as a result, led to an improved sense of empowerment. The study contributed to improve our understanding of empowerment in health care. It showed that the environment and culture of information sources could enhance or diminish an individual's sense of empowerment. In particular, the attitudes and norms to provide, share and exchange various information, values embedded in the source and quality of the shared knowledge did not only influence how people viewed the condition but also their role in the management of the condition and how they validated/ trusted other information providers. The study clearly showed that patient empowerment is affected by different personal resources, personal, contextual and intrapersonal factors and by factors and values embedded in the used source of information.

Second, the study's data showed that there was an apparent tension between people with T2D, care providers and the health care system. To understand this tension, the Social Ecological Model (Section 2.3.4.6) and various types of the doctor-patient relationship (Section 2.6.4) were introduced in Chapter 2. In the analysis and discussion of the first study's findings (Section 4.4.2), the model was used to understand how public policy, organisational, community, interpersonal and intrapersonal factors influenced people's behaviour in the study. The model showed that care providers' policies, actions and relationship with various sectors often conflicted with patients' desire. The study explained

that the policies were interpreted and applied differently, which caused disagreement and dissatisfaction among patients. The study contributed to the knowledge by explaining that connecting to others who face similar challenges might help understand these hierarchies of factors and overcome various challenges. Various members, for example, challenged the decisions of their HCPs after they learned (from other OSG members) that a specific policy is interpreted differently by other care providers. They learned about how policies were applied, became aware of their legal rights and objected to their HCP decision to a higher authority.

In relation to the doctor-patient relationship, the analysis showed that various relationships existed in the data of both studies (Sections 4.3.2.2.2 and 5.3.2.2.2). However, most members and participants reported that they had a paternalistic relationship where there was little involvement from their side. The findings clearly showed that most members and participants of the study would have desired to form a mutuality relationship. This desire, however, was not always welcomed by HCPs. The study explained that the use of OSGs increased this desire for involvement in one's own care and when HCPs do not support this desire, they tend to rely on other OSG peers to support their health actions. OSG peers, as a result, could serve a support system for those in a paternalistic relationship, desire more involvement in care and not supported by their HCPs.

Third, the Health Belief Model (introduced in Section 2.3.4.4) was used to understand various health behaviours adopted by members and participants of the present study. The model explains that, to take a health action, individuals evaluate the seriousness and susceptibility to the disease or its consequences and the perceived overall benefits from undertaking the action. The model also suggests that various causes and modifying factors influence the action. The model was powerful in understanding multiple findings. For

example, Sections 4.3.2, 5.3.2.2.1 and 6.2.1 utilised the model to understand the factors that motivated members and participants to seek information about the condition, change some of their old health behaviours and adopt new ones. It also provided a more profound understanding of what demotivated individuals from taking action and why/how people differed in changing their health behaviours. The findings of this study supported some versions of the model that included two other constructs (i.e. perceived self-efficacy and self-involvement) to the model (Section 6.2.2). The study showed that these two constructs were found to be critical for individuals in the study to take actions regarding their health.

While the HBM was powerful in understanding people's health actions, Wilson's (1999) model was helpful in providing insights on factors that might influence information behaviours. The study utilised Wilson's model to provide insights on what motivated people to seek information (Section 6.2.1). In particular, the study provided a novel contribution to knowledge by outlining the information journey of the members and participants in the study (Figure 6.1). In the analysis of the journey, the study explained that both the HBM and Wilson's model could be used to understand people's health and information behaviours. Figure 6.3 showed the action sequence of information seeking and health action motivators and barriers identified in this study. The study provided greater insight on how the intersection of both health and information behaviours could be understood.

Lastly, the study utilised three other theories and models to understand various behaviours. For example, The Transtheoretical Model (introduced in Section 2.3.4.1) was used (in Sections 4.4.3 and 5.3.2.2.3) to understand the type of support members and participants needed in a particular stage of change. As the model shows that people go through six main

stages of change when adopting a new behaviour, this study showed that members and participants sought different types of support from their OSG peers in various stages. This improvement of understanding patient's needs could be useful in helping people with T2D when changing their health behaviours. Similarly, The Social Cognitive Theory (introduced in Section 2.3.4.2) was applied to understand how environmental and personal factors can influence individual's health behaviours. The present study's findings (Section 6.3) showed that OSGs could serve as an influencing environmental factor that leads to a change in members' health behaviours even for non-poster (i.e. lurkers). The study explained that the benefits of connecting to other peers (e.g. via OSGs) is contagious and not only limited to active posters. Finally, the study identified various roles that members and participants performed in the OSGs (Section 6.3). To understand the needs of each role, the Uses and Gratifications Theory (introduced in Section 2.3.4.6) was applied (Table 6.3). The theory was powerful in understanding members and participants online behaviours. It explained that each role might satisfy one or more needs. The study provided novel insights on the online behaviours of OSG members and the needs that each role satisfies.

## **6.6 Conclusion**

The purpose of this chapter was to discuss the findings of both studies from Chapters 4 and 5. This chapter identified the information journey for the participants in the study and showed how they differed in their information seeking and using behaviors. The selection of information sources was discussed including the discussion of the impact that different sources had on patients' self-efficacy and their perceived self-involvement. This was

presented in relation to the Health Belief Model. The chapter then presented and described a number of roles undertaken by OSG member that were identified in the results and how they were undertaken by the participants. This provided a deeper understanding of activities performed in these online communities and how people varied in carrying them out. Finally, the chapter brought together all of the factors influencing patient empowerment identified in the present research and discussed these in relation to the HCE model. A core contribution of this thesis to the HCE model was also explored.

The final chapter of this thesis, Chapter 7, will summaries the findings of this thesis and its main contributions, the impact of these findings and contributions to the existing body of knowledge, recommendations for academics and practitioners, as well as the limitations of the study.

## **CHAPTER 7 : CONCLUSIONS AND IMPLICATIONS**

### **7.1 Introduction**

The research presented in this thesis has substantially enhanced the knowledge and understanding of the role of OSGs in empowering people with T2D in the UK. The findings increased the knowledge on information seeking and using behaviours for people with T2D using OSGs, their digital behaviour and its influence on their level of empowerment. The findings were discussed in the context of various information, health and empowerment theories and models (Chapter 6), which contributed to improving the theoretical understanding of people living with T2D. This chapter concludes the thesis and explains how the major findings across all of the phases of the study address the original research questions (Section 7.2). In light of the findings, the contribution to knowledge in relation to theory (Section 7.3), methods (Section 7.4), practice and policy (Section 7.5) are discussed. Finally, the chapter presents the limitations of the research and makes recommendations and suggestions for future research (Section 7.6).

### **7.2 Revisiting the research questions**

The present research set out to answer the following over-arching research question:

**How can OSGs influence patient empowerment for people with Type 2 diabetes?**

To answer the main research question, the following three sub-questions were pursued:

**Q1. What are the information needs and behaviours of people with Type 2 diabetes using OSGs?**

This study found that most participants received limited or no information about the condition and its consequences at the time of the diagnosis. While some participants were



proactive, and started to search for information prior to, or immediately following the diagnosis, others waited until they received official information through personal meetings with HCPs or attended the DESMOND course. Even those who attended the official information sessions reported that the information provided was limited. Most members and participants explained that authorities provided standard, non-personalised information without considering individual factors and preferences. Furthermore, since the condition is not static in nature, the participants needed continuous information support to effectively self-manage the condition. This led them to find alternative sources of information to fulfil their information needs.

Table 7.1 below summarises the information needs identified for members and participants in the current study. As Table 7.1 shows, understanding diabetes and useful diet options were found to be essential information needs for members and participants in the present study. Many of them had basic questions about what T2D is and how to cope with it. Other needs included information about medication, physical activities, and self-monitoring of blood glucose levels.

**Table 7.1 Summary of information needs of the members and participants in the study**

<i>Category of information need</i>	<b>Example of the type of information</b>	<b>Example from the data</b>
<i>Understanding diabetes</i>	<ul style="list-style-type: none"> <li>• Interpretations of blood sugar level test results.</li> <li>• Impact of carbohydrates on people with T2D.</li> <li>• Hypoglycemia.</li> <li>• Side effects of diabetes.</li> </ul>	<p><i>“Much of [what I was looking for] was supporting information on what particular numbers mean and how to rationalise some of the information that you get so you know what the HbA1c figures mean in context, how long people have been working at it and how numbers change” (Harry, The Interview Study)</i></p>
<i>Food</i>	<ul style="list-style-type: none"> <li>• Diet plans.</li> <li>• Recipes.</li> <li>• How to read food labels.</li> </ul>	<p><i>“I’m reading now and learning about different recipes on this OSG that I can prepare and eat during lunch breaks and snacks” (1- Bryan, The Analysis of the Posts Study)</i></p>
<i>Medications supplements and vitamins</i>	<ul style="list-style-type: none"> <li>• Types of supplements and vitamins that are useful for people with T2D.</li> <li>• How to take them.</li> <li>• Common side effect(s) of medications.</li> </ul>	<p><i>“After reading about the acid here, I have tried it for around three weeks. My blood sugar levels are kind of lower and my feet pain is significantly reduced!” (1- Mary, The Analysis of the Posts Study)</i></p>
<i>Physical activities</i>	<ul style="list-style-type: none"> <li>• Types of activities encouraged for each person depending on their health and age.</li> </ul>	<p><i>“I joined threads where like kind of where we do the exercise and we discuss the plan of gym and what you have done today” (John, The Interview Study)</i></p>
<i>Self-monitoring of blood glucose</i>	<ul style="list-style-type: none"> <li>• Why, how and when to self-monitor.</li> </ul>	<p><i>“I got a test metre after I joined the forum because I didn’t even know you could buy test metres at that point” (Alice, The Interview Study)</i></p>
<i>Patient-doctor relationship</i>	<ul style="list-style-type: none"> <li>• How to practically communicate with HCPs.</li> </ul>	<p><i>“What should I have said to my HCP, so he listens to me and reduces the medication that makes me sick?” (2- Millie, The Analysis of the Posts Study)</i></p>
<i>Legal rights</i>	<ul style="list-style-type: none"> <li>• Illustration of patient’s rights.</li> <li>• Recommendations to obtain legal right.</li> </ul>	<p><i>“I went through the NICE guidelines in detail... I wrote to the CCG explaining my justifications... My HCP was then able to prescribe me testing strips again” (2- Isla, The Analysis of the Posts Study)</i></p>
<i>Products and practical recommendations</i>	<ul style="list-style-type: none"> <li>• How to effectively track food intake and blood sugar levels (e.g. keeping a food diary and results of HbA1c tests).</li> <li>• Economical ways to find various products (e.g. vitamins and blood testing equipment).</li> </ul>	<p><i>“Where can I find the cheapest place to buy Tee2 strips?” (1- Evan, The Analysis of the Posts Study)</i></p>

This study showed that the fulfilment of an information often led to a new need for information. Moreover, in their journey to satisfy their information needs, study members and participants often encountered new information (i.e., new approaches and techniques to manage and control T2D) that interested them and which, therefore, created new information needs. Much of this information was not supported by HCPs, and this led members and

participants to rely on peers within the OSG to provide information on these approaches and techniques. Interestingly, OSGs that offered new information (i.e., new approaches and techniques to control and manage T2D) were the preferred sources of information. This showed that the majority of participants were not interested in seeking information similar to that provided by their HCPs. They believed that the information provided by HCPs was insufficient to help them achieve desired health outcomes or they did not trust it. Therefore, they preferred the sources that provided new information.

## **Q.2 How do patients with Type 2 diabetes utilise the information they receive on OSGs and how does this influence their health behaviours?**

Participants varied in how they utilised the information obtained from OSGs. The majority of participants explained that it depended on the type of information (e.g., information about diet was not deemed to be as important as information about medications; for example, reducing the amount of carbohydrate intake was deemed less important than changing the dosage of a medication). They varied in the level of trust they placed in the information provided by their peers. Some explained that they did not trust such information blindly (i.e., they had to search for that information via different sources before trusting it). Others explained that they would trust other members who shared their progress and achieved good health results. Some participants relied on the ‘wisdom of the crowd’ to confirm the information shared by other members. In other words, they would ask other members about the information and judge on how extensive the agreement was (i.e., how many members supported the information versus how many members rejected it).

When the participants accepted the information they found on the OSG, and wanted to apply it, the majority explained that they would apply it gradually with continuous monitoring of

their blood sugar levels. For example, if they were convinced that a low carbohydrate diet would help them, they would decrease the number of carbohydrates by small amounts and self-monitor their blood sugar levels before, during, and after the application of the change in diet. They would then consider whether to persist with the change, based on the reaction of their body to the change.

This study showed that experience-based medicine was preferred over evidence-based medicine. Study members and participants clearly explained that they would apply information that helped them control and manage their T2D, regardless of there being medical evidence that proved it had no long-term side effect.

This study further showed that information support was largely needed before and during performing a new health action, in order to understand the new health action and fulfil any information needs that resulted from the application of the action. Emotional support, in contrast, was found to be needed in the first period of applying a health action and lasted for a longer period of time. This was needed to encourage the individual to adopt and maintain the action until it became a behaviour.

### **Q3. How do the various contextual and intrapersonal factors and personal resources influence patient empowerment for people with Type 2 diabetes?**

As discussed in Section 6.4, various factors influenced patient empowerment among people with T2D using OSGs. These are summarised in the following:

- **Contextual factors:** These factors represented the context in which a person lived.

This study found that they largely differed between participants and influenced how

they managed and controlled their health. In particular, the culture, background and personality of the individual, as well as the perceived norms, informed how people with T2D in the UK utilised the information they searched from sources such as OSGs. This was especially clear when the information found in the OSGs was different from that provided by HCPs and was not supported by the medical evidence. Some of the members and participants explained that it was not easy for them to challenge HCPs and apply information that was not supported by them. This suggests that, while the majority of the members and participants in the present study preferred experience over evidence-based medicine, there might be other people who cannot utilise the same information because it is not endorsed and thus not supported by their HCPs. This would result in a lack of trust by people in applying it or delaying doing so. While it was not possible to compare these people with the members and participants of the current study, the results showed that when the members and participants of this study were active in information seeking and using it, regardless of agreement with the HCP, they achieved better health outcomes. This allowed them not to feel restricted by certain information but to feel free to try different approaches and techniques until they found the ones that worked for them. As a result, this led them to achieve better health outcomes, which also enhanced their sense of empowerment.

Similarly, the background, education, training and culture of HCPs influenced how they supported patient choices. This is a critical element in how the patient-doctor relationship is formed. Members and participants who had HCPs who supported their decision making, described a better relationship with their care providers and the health care system in general. A supporting relationship does not necessarily mean

that HCPs had to agree with the information provided by the patient. Members and participants wanted their care providers to provide the information they thought was best for them and accept the patient's decision to follow that or other information without conflict.

- **Personal resources:** this study showed that different personal resources contributed to the way in which participants searched and utilised information and, therefore, their level of empowerment. For example, the social circle surrounding individuals and their previous experience with other health conditions was found to influence how they searched for, and used, information. Various participants explained that their spouses did not support them in applying information that was not supported by their HCPs. Others described how their experience with previous conditions helped to form a belief that the information provided by HCPs was inadequate.
- **Intrapersonal factors:** people with T2D move through different psychological states when managing their condition which affected their involvement in the control and management of their condition. The present study found that managing T2D entailed many emotions. Various members and participants reported that the management of the condition was overwhelming and included serious negative psychological states, including having suicidal thoughts. This caused them to become disengaged from the management of the condition and negatively influenced their sense of empowerment. However, being in a supportive community with members who share the same challenges can help them overcome such emotions and build hope that helps them tolerate the uncertainty of the condition.

Additionally, the perceptions and beliefs of individuals regarding their role in their health were found to be critical in terms of the degree of involvement they had in their health care. Various members and participants explained that they thought that they had to take only a few actions to manage their T2D (e.g., take medication and eat less sugar). However, their involvement in OSGs and observation of other successful members changed this perception. They realised that they had to be more active in the management of their condition, discover what worked for them, change some behaviours and stay committed and involved. This shift in beliefs and attitudes changed their empowerment status enormously.

- **Factors related to information sources:** This new set of factors was identified by this study and found to influence patient empowerment. They represented factors related to the culture and environment of the information source. This study showed that information sources differed in their values and attitudes and this highly influenced the information exchanged among OSG members. Sources that allowed for the exchange of various types of information freely, supported personalised treatments, encouraged a culture towards patient involvement in care, were found to have more influence on empowering their members.

### **7.3 Contribution to knowledge**

The interdisciplinary research presented in this thesis makes various noteworthy contributions to existing knowledge. It investigated and contributed to an increasingly important and critical discussion about patient empowerment. First, this research filled the gap identified in the existing literature (Section 2.9) related to the role of OSGs in patient empowerment for people with T2D in the UK. This mixed-methods qualitative study is the first to carry out an

in-depth analysis of OSG posts and semi-structured interviews about the role of OSGs in empowering people with T2D in the UK. Whilst OSGs and patient empowerment have been separately studied by various scholars, the role of OSGs in empowering patients (in the current context of people with T2D) is a neglected area of research. This study focused on a particular geographical context (i.e. the UK) to outline how the health care system and its policies in relation to T2D might influence patient empowerment. It provides new insights into how empowerment operates by focusing on a specific chronic condition that is largely managed by the patients themselves. This study goes beyond understanding the role of OSGs in fulfilling the informational and emotional needs for people with T2D. Rather, it attempts to understand the formation of these needs, the utilisation of the information obtained and the outcomes resulting from the application of the information. The study shows how OSGs have the potential to transform how patients interact with each other to improve their knowledge and overcome the limitations resulting from their interactions with their HCPs. Interestingly, engagement in OSGs did not only fulfil the informational and emotional needs of their users but also changed how patients perceived their role in care.

Second, this study extends current understanding by revealing the challenges faced by people with T2D. It highlighted the fact that, for people to gain power over their health, their choices and decisions must be considered. It shows that when HCPs are the dominant component of the patient-doctor relationship, this might lead to disagreements or arguments about various potentially controversial topics with patients who want to be involved in care. As a result, this can lead to a tense relationship with HCPs and hinder patients' self-engagement in their own care.



Third, through its theoretical and empirical engagement, this study has expanded the ways of understanding the online behaviours of people with T2D within OSGs in the UK. While previous studies have classified online community users based on their registration status (e.g. Han et al. (2012) classified users into lurkers, posters and non-users), role in the discussions (e.g. recently Rehman et al. (2020) grouped users into conversation starters, influencers, active engagers, network builders and information bridges) and contribution patterns (e.g. Akar et al. (2019) categorised users as visitors, socialisers, content generators and passive members), the current research provided a deeper understanding of the different roles and corresponding needs of users of Diabetes OSG. It explained the occurrence of the roles and their characteristics. It also showed that the reciprocity behaviour for online members might not be limited to the same online community, but to a wider population of people with T2D. This advances the understanding of OSG user behaviours which was reported to be key for the successful management of such communities (Akar et al., 2019).

Fourth, this is the first study on OSG for people with T2D that has developed an ‘information journey’ (see Figure 6.1) for people with T2D using OSGs in the UK. The diagram shows that participants differed in their information-seeking behaviours and that this influenced their health outcomes (e.g. knowing various treatment methods helped them improve their management of the condition). For example, their health literacy, knowledge about their right in using the care system and the condition and treatment options were enhanced. As a result, their health status/ management and control of the condition improved. In this study, the majority of participants were found to have deteriorated health outcomes until they actively engaged in OSGs. For example, many participants explained that when they followed the information provided by their HCPs, their management of blood sugar levels improved but they were still struggling with the side effects of the condition. When they engaged in the

OSGs, their knowledge and skills improved which, in turn, enhanced their health status and management of the condition. They mostly started their information seeking within the OSGs following official diagnosis. Figure 6.1 sheds new light on the potential harm that gaining knowledge through OSGs had on the trustworthiness of care providers. The diagram outlines various paths and outcomes of the participants' journeys. However, further research is needed to investigate other potential journeys and outcomes. To the author's knowledge, this is the first study that has explained why trust in HCPs was affected for people with T2D using OSGs and how the business model of OSG hosts and their associations (e.g. through sponsorship) with other organisations might influence the credibility of the OSG.

Fifth, this study employs various theories to further extend our understanding regarding a number of issues. For example, the Social Ecological Model (see Section 4.2.2) was employed to understand the power hierarchy of the controversial topics found in the analysis of OSG posts. The model was employed to show that various institutional, community and policy factors can influence the beliefs, knowledge and skills of individuals. The findings here supported the factors outlined by the model and described how they operated in the context of the present study. The HBM was used to understand the motivations of information seeking identified in the findings (see Sections 4.4.3 and 5.3.2.2.1). The findings supported the importance of the *perceived susceptibility* and *seriousness* of the condition as well as the factors that *cues to action* in making a health action. The study also outlined the importance of considering environmental factors (e.g. health care providers) in the model, as they might influence the promotion or prevention of taking the action. The Transtheoretical Model was used to interpret the needs of the members and their seeking activities (see Section 4.4.3). This added to the model that individuals vary in their informational and emotional needs based on their stage of change. Wilson's Information Behaviour Model and

the HBM were used to understand the sequence of the occurrence of information seeking and health action motivators and hindrances identified in this study (see Section 6.2.1). The current study adds to the knowledge that various constructs of the two models can be combined and used to better understand the sequence of occurrence of seeking information and performing health actions. Other theories such as the Social Cognitive Theory and Uses and Gratifications Theory were employed to understand the online behaviours of participants of this study (see Section 6.3). The application of these theories and models therefore advances the interpretation of the findings, enhances our understanding of the topics and extends the use of such theories and models.

Sixth, from a theoretical point of view, the present study revealed a novel contribution to the existing knowledge of health behaviours and online empowerment. This study supports the work of other scholars, e.g. Rosenstock et al. (1988), who highlighted the importance of the inclusion of *perceived self-efficacy* as a separate construct to the HBM (see Figure 6.4). It stresses that this construct is vital for long-term health behavioural change. The study also suggested the inclusion of *perceived self-involvement* as an activation construct to *perceived self-efficacy* (see Figure 6.5). Thus, the findings of this study highlight that when patients change their perception about their role/involvement level, their self-efficacy can therefore be influenced.

Finally, this is the first study to examine the empowerment of people with T2D using OSGs in the UK using two in-depth qualitative methodological approaches. Additionally, the study is the first to use the HCE model to investigate how empowerment operates. This study shows that empowerment is not a linear process that can be easily followed. Rather, it a complex process that has many contributing factors. As such, this study showed how various

factors were found to influence each other as well as patient empowerment for the OSG members and participants in the current study (see Table 6.4). More importantly, the study added a novel contribution to the HCE model, by introducing a new set of factors found to influence patient empowerment. Factors related to information source culture and environment were found to be critically important. These factors explained how information providers can differ and the implication of this for information seekers. For example, these factors explained the elements that differentiated between the OSGs included in this thesis and, as a result, the health outcomes and sense of empowerment their members reported. This study makes it clear that patient empowerment is not only influenced by various personal resources, contextual and intrapersonal factors, but also by factors and values implemented in the source of information.

#### **7.4 Methodological contribution**

An inductive approach was chosen to enhance the chance of discovering unanticipated empowering factors, online information seeking and using behaviours for people with T2D using OSGs, the dynamic nature of empowerment elements and challenges that members and participants face to implement them, online behaviours that take place in OSGs and to analyse the impact and implications of using such communities. This study has drawn its conclusions from a large volume of data through the combination of two data-collection techniques: the thematic analysis of threads (described in Chapter 4) and posts from three UK-based OSGs and qualitative, in-depth, semi-structured interviews with OSG users that have T2D and live in the UK (Chapter 5). The combination of different types of data offered an effective and deeper understanding of the research questions from various angles. Additionally, it enhanced the validity and quality of the study since the online threads and posts were combined and checked against the experiences of the interview participants. The

combination of the two methods also helped the researcher to develop a better understanding of the subject matter under investigation. The data collection and analysis of online posts introduced the researcher to the topic and nature of discussions that take place in UK-based, T2D OSGs, as well as to discover critical issues for OSG users. This, therefore, equipped the researcher with a good knowledge about the communities and this, in turn, allowed the researcher to better design and conduct the interviews in a way that maximised the understanding of the experience of the participants. Therefore, this study emphasises the importance and value of the sequence of the two methods to achieve a better understanding of the subject.

Another area of methodological contribution was that this study examined a high volume of data gathered from more than one OSG, each with a different organisational structure (i.e. one of the OSG belonged to a community-profit organisation, another was owned by a charity and the third was created and operated by individuals). The variety of the OSG types included showed that the history and values of the information source might influence information sharing in OSGs, as well as the sense of empowerment for their members.

The present study contributed to Internet research by explaining that, although the Internet is an open space that overcomes geographical boundaries, factors related to the geographical location (i.e., the country and its health care system and structures) of the online community might highly influence the culture of the community and information being exchanged. This study showed that the challenges arising from the interaction of the health care system and care providers are reflected in the community.

## **7.5 Recommendations for practice and policy**

The findings have various implications for practice and policy and are likely to be of direct interest to care providers and OSG moderators as explained in this section.

### **7.5.1 Health care professionals and the health care system**

- Being diagnosed with T2D was emotionally difficult for most users and participants in the study. It is recommended that when HCPs are preparing to inform the patient about their diagnosis, they should place more emphasis on possible negative reactions than appeared to be happening for the people in this study. This also suggests providing HCPs with training that helps them mitigate possible negative reactions.
- Various users and participants explained that HCPs gave them the impression that T2D is very progressive and patients have limited or no chance to stop the progression. While HCPs are advised to inform patients about the possible progression and consequences of T2D, at the same time, it is recommended here that they should be advised to help patients to build resilience and hope.
- The negative reaction of patients to the diagnosis was especially noticeable when there was a lack of information provision. This study found that the absence of information provision, or the provision of low-quality information (e.g. a photocopied paper of the Eat Well Plate) at the time of diagnosis caused feelings of confusion and isolation. This study, therefore, recommends that the diagnosis should be accompanied by a personal meeting with care providers, in which the latter provide a sufficient amount of information and discuss the concerns of the patients. The provision of appropriate, satisfactory, understandable and well-timed information is extremely important both for the well-being of the patient, but also to support their longer-term health.

- Although some scholars (e.g. Kim et al., 2020) reported that some patients preferred not to be provided with information at the time of diagnosis, HCPs can assist if the patient is interested in receiving information and is able to process it. It is recommended here that HCPs should refer patients to other sources of information (e.g. OSGs) that they can access whenever they have an informational need.
- The study showed that patients have different informational needs at different points in time regarding their management of the condition. It also explained that the fulfilment of a need might create another need. The study additionally explained the various challenges that prevented patients from having effective communication with their care providers (e.g., limited appointment time). Other scholars have explained that some patients preferred not to attend the official face-to-face educational sessions provided by the care system (e.g., Chatterjee et al. (2018) reported that less than 6 percent of people with T2D in England and Wales that were offered face-to-face educational sessions actually attended them). This, therefore, supports the previous recommendation that patients should be referred to other sources of information to satisfy their ongoing needs.
- The current study highly recommends referring patients to various OSGs. This study found that being with other members who faced similar challenges and concerns helped gain a sense of empowerment. OSGs have the potential to help patients overcome various limitations that resulted from their interactions with HCPs. OSGs can be a cost-effective tool for the health care system to strategically utilise them to enhance the standard care provided to people with T2D.
- The study showed that people with T2D not only have informational needs but also emotional and psychological needs: satisfying these needs is equally important as satisfying the informational ones. This study showed that members and participants

were eager to find a source of support that fulfilled these needs (e.g., Diabetes UK (2018) explained that 76% of people with diabetes in the UK were not offered emotional and psychological support). Unfulfilled psychological needs might result in poor self-management of the condition and reduced quality of life (Kalra et al., 2018). The present study demonstrates that recommending OSGs to patients might not only satisfy their informational needs but also improve their emotional and psychological status, and ultimately their health outcomes.

- This study stressed the importance of involving the patient in the management of their condition. A partnership should be formed between the patient and care providers. In this relationship, care providers should inform the patient about the available treatment approaches and options and advise them about what they believe is the best recommendation for the patient. If the patient decides to follow other approaches, HCPs are advised to respect their decision and work with them. Blaming the patient or involving them in continuous tensional arguments might contribute to the failure of the patient-doctor relationship. This study showed that, as a result, patients may end up managing their condition by themselves without the engagement of the care providers.
- The movement towards, and focus on, “person-centred approach”, “shared decision-making”, “personalised care planning” (NHS England, 2014a, p. 22), and “empowered patients” (NHS, 2019, p. 93) have been repeatedly included in the strategic plans of the health care system in the UK. This was especially noted for long-term conditions such as T2D (NHS England, 2014b, 2014a). However, the current study shed light on a gap in implementing such concepts. Whilst the health care system aimed to apply them, various HCPs showed that they were not able to work within a patient-doctor relationship that allowed the application of such



concepts effectively. This might suggest the need for continuing professional development and training for care providers to enhance their skills and change their perceptions of the patient-doctor relationship.

- HCPs are recommended to acknowledge the efforts of the patients to improve their own health (i.e., their online information-seeking behaviours). They should discuss their findings and consider their preferences.

### ***7.5.2 OSG moderators and owners***

- This study showed that members and participants differed in the extent to which they engaged in the OSGs, particularly when they first found them. Some older people explained that being a member of such a community was not normal for them. Engaging in small closed online communities encouraged some of them to subsequently join larger open OSGs. This helped them overcome their fear of interacting with thousands of members. OSG moderators are therefore encouraged to create small groups for such users to encourage them to overcome these kinds of fears.
- This study showed that OSGs differed in the type of information their members exchanged and the values embedded in the communities. Whilst some OSGs mainly represented the information recommended by the health care system, others allowed their members to share information that was not necessarily recommended by the health care system. This created a culture of independence and encouraged members to be active in seeking personalised treatment. OSG owners are therefore encouraged to implement such values and cultures since they were found in this study to enhance patient's sense of empowerment.

- The results showed that many OSG members engaged in tensional discussions that might have caused negative consequences to their relationship with the online community. The members were not allowed to express their opinions freely. OSG moderators are therefore advised to allow the discussion of such topics whilst it does not involve personal sensibilities. Constructive discussions are helpful for OSG members to understand controversial topics regardless of the position of OSG moderators on that topic.
- This study showed the different roles that OSG members performed in the community (Section 6.3). For example, they can start as *information seekers* and subsequently develop into *information exchangers* or *providers*. The latter represent a minority number of the whole community but they contributed with the most posts. OSG moderators, therefore, are recommended to encourage *exchangers* to become *providers* in the community. This will help the community to grow as it will have more experienced and active users on the long term who are willing to help new users.

## 7.6 Limitations

Although this thesis was successful in investigating the outlined research questions and advancing the understanding of the role of OSG in patient empowerment for people with T2D, the inevitable time frame of the PhD project which, inevitably, influenced the scope and objectives of the study, implied that other ideas that arose from this study could not be pursued. A number of potential limitations may have influenced the results obtained as follows:

- The study employed a mixed-methods qualitative approach to investigate the research questions. One disadvantage regarding this methodology is that the results are not representative because of the response bias. People that took part in this study saw the

advantage of using OSGs and, therefore, were willing to participate in the study. It is possible that there were others that did not see this advantage and, therefore, were not interested in taking part or even did not notice the recruitment call. It is also possible that more vocal users might have volunteered. Therefore, the results of this qualitative approach are not generalisable to a wider population. Although the purpose of qualitative methods is to provide an understanding of a given human phenomena (Creswell, 2009), the extent to which these phenomena could be transferred to other similar groups (e.g. other conditions or countries) would need to be tested through using quantitative methods.

- In the analysis of OSG posts study, the selected two-month timeframe for data collection might have restricted the representation of the information exchanged between OSG members. Although three OSGs were examined, threads and posts included in this study were purposively selected from general sections/ discussion boards that were dedicated for T2D discussions. The sample size and the selection criteria for both the post and interview studies, therefore, might not have reflected the experience of other OSG users and discussions. Additionally, the majority of the members and participants of both studies were female. This, as a result, may have affected the transferability of the findings to other contexts.
- Although the study was successful in recruiting two silent OSG users and revealed interesting insights about their use of OSGs (Sections 6.3), the vast majority of the participants in the interview study were active in the OSGs and also in the management of their conditions. The impact of silent engagement with OSGs on some users is still unknown. The picture thus remains incomplete.
- The data collection in both studies (Chapter 4 and 5) focused on particular participants: people with T2D who used OSG in the UK. These participants were

actively engaged in information-seeking in OSGs at the time of the data collection. It is expected that there are users who join the OSGs and exit them for various reasons without gaining any noticeable health improvement (as explained above). The present study was not able to investigate the impact of OSG use on users that did not benefit from their use.

- Furthermore, the present study was unable to investigate the point of views of people with T2D who did not want to be actively engaged in the management of their condition. As explained previously, the participants in the current research were active in finding information that enhanced the management of their condition and demanded an active role in their relationship with their care providers. These people might be considered active patients wanting to gain control over their health. OSGs, therefore, were facilitators in equipping them with the knowledge and skills required to be empowered. It is expected that there are many patients who are less active or non-interested in taking active role in the management of their condition. These patients might prefer a more paternalistic relationship with their care providers as explained in Section 2.7.4.2. The findings of this study, therefore, may have reflected the voice of people with T2D that preferred to be active in the management and control of the condition. This, however, is not the case for all people with T2D.
- Similarly, the present study only examined the perspective of people with T2D. It was not possible to investigate the point of view of HCPs supporting people with T2D. This is important as the findings of this study revealed a tensional relationship between care providers, the care system and people with T2D, and what was reported here was very much a one-sided view.
- Given the limited time of the Ph.D. research, the study focused on one condition (i.e. T2D) in one geographical location (i.e. one country, the UK). The study chose to

investigate this condition because of its prevalence, its cost on the health care system and its nature, demanding patient to manage and control the condition by themselves (see Section 1.2.1). This, therefore, meant that the study did not investigate insights related to the role of OSG in empowering patients that might be present in other long-term conditions or countries. It remains unknown whether the findings of the present study are relevant to other long-term conditions/ countries or not. For example, it is unknown if people with other chronic conditions face tensional patient-doctor relationships because of controversial treatment approaches or whether the elements that influenced patient empowerment identified in this study affect people with other chronic conditions, as well, or not.

- Although most members and participants to the study reported an increased sense of empowerment after using the OSGs, the study was limited in examining the accuracy and validity of the information exchanged and whether the felt sense of empowerment was subjective or objective.

## **7.7 Future research**

Given the above limitations, this study suggests the following directions and opportunities for future research:

- The results of the study provided important findings that have implications for policy and practice, which should be validated by a larger sample size. Future quantitative studies need to be carried out to check the applicability of the findings on a wider population of OSG users. This would enhance the generalisability of the study and provide a deeper understanding of the findings.
- Similarly, the results of this study showed certain cultures and norms for the members and participants of the study. In particular, the study explained that members and

participants expected their HCPs to accept and encourage their involvement in care.

However, further quantitative research is needed to explore the norm and patient involvement culture for people with T2D in the UK.

- Future studies could include a larger sample from different diabetes OSG sections (e.g. some OSGs have dedicated sections for food, vitamins and physical activities) to further understand the information behaviours of OSG users.
- Future work could also use other timeframe for data collection and recruitment criteria to see if the findings of the study are transferable to other similar contexts or not.
- The thesis identified various potential information journeys and outcomes for the participants in the study (see Figure 6.1). It is, however, expected that there are other paths and outcomes for other journeys as the figure explains. For example, the journey of people that relied on HCPs only as a source of information, used other sources of information (not including OSGs) or used OSGs but did not gain benefit from using them are still unknown. The focus of the present study prevented identifying these journeys and outcomes. Future studies, therefore, are recommended to investigate the information journeys and outcomes of other people with T2D. This, as a result, will improve our understanding about the information needs and behaviours of people with T2D and allow researchers to compare the experience of using different sources of information.
- Future studies on the current topic are recommended to try and understand the experience of using OSGs for silent users and those who use them and exit the communities. This will help understand the experience of using OSGs for a relatively obscure population.

- Likewise, further work could be carried out to understand the perception of patients who prefer not to be actively involved in the management and control of their T2D and compare them with patients who are actively involved in care (such as the participants of the present study), in terms of their belief(s) regarding the role of patients in care. This would improve our understanding of how to engage a wider population of people with T2D in the management of their condition, which in turn might improve their sense of empowerment and health status.
- As explained in the Limitations Section above (7.6), future studies could investigate the other side of the patient-doctor relationship (i.e., HCPs and the health care system). In particular, investigating their point of views regarding patients' involvement in the patient-doctor relationship and the freedom to discuss various information/ treatment approaches and techniques would help to develop a better understanding the tension created between the two sides (i.e., patients and doctors) and, as a result, how it could be resolved. This would be a potentially fruitful area for further work.
- Whilst this study takes T2D as a condition to investigate the role of OSGs in empowering patients in the UK, it is also suggested that future studies examine other long-term conditions and compare the results of this study among various conditions. For example, the findings showed that the members and participants of both studies always highlighted the importance and the responsibility of the role of patients in taking care of themselves. They explained that, for people with T2D to achieve better health status, they have to stay active and focused on the management and control of the condition (e.g. see Section 6.2.2). Future studies are recommended to investigate if (or not) such findings/ values are present in other people with other chronic conditions using OSGs. This would increase the understanding of the extent to which

the information behaviours and empowerment processes specific to a given condition or the extent to which these behaviours are common to other conditions.

- Similarly, investigating the same research objective for other geographical locations (i.e. other countries) and comparing the results with the current study might show the extent to which the UK NHS system might be a factor, as well as cultural and contextual factors, to influence online information-seeking behaviours and patient empowerment.

## **7.9 Closing statement**

This study showed that OSGs might help to fulfil the information and emotional needs of people with T2D. They have the potential to transform how patients engage with each other and overcome the limitations of their interactions with their HCPs. The exchange of experience-based information in OSGs was found to enhance patients sense of empowerment.

Patient empowerment should not be perceived as a secondary element of health care but as a core component of the care, especially for chronic conditions such as T2D. Whilst there are some people with these conditions who prefer not to be active patients, many others spend a significant amount of time and effort to try to find out how to gain control over their health. They, and their choices, therefore, must be considered as a main component of the treatment plan. The dynamic in the patient-doctor relationship, therefore, must adopt such involvement of the patient. Failure to accept such involvement might result in a tensional relationship detrimental to the long-term health and well-being of patients.



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## Appendices

### Appendix 1 Ethics application for the OSG Posts Study



# Application 016206

## Section A: Applicant details

Created:  
Tue 22 August 2017 at 15:36

First name:  
Abdulaziz

Last name:  
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Programme name:  
PhD

Module name:  
PhD

Last updated:  
17/11/2017

Department:  
Information School

Date application started:  
Tue 22 August 2017 at 15:36

Applying as:  
Postgraduate research

Research project title:  
The Role of Online Support Groups in Empowering Type 2 Diabetes Patients

## Section B: Basic information

### 1. Supervisor(s)

Name	Email
Peter Bath	p.a.bath@sheffield.ac.uk

## 2: Proposed project duration

Proposed start date:  
Wed 1 November 2017

Proposed end date:  
Sun 31 January 2021

## 3: Project Code (where applicable)

Project Code  
- not entered -

## 4: Suitability

Takes place outside UK?  
No

Involves NHS?  
No

Healthcare research?  
No

ESRC funded?  
No

Involves adults who lack the capacity to consent?  
No

Led by another UK institution?  
No

Involves human tissue?  
No

Clinical trial?  
No

Social care research?  
No

## 5: Vulnerabilities

Involves potentially vulnerable participants?  
Yes

Involves potentially highly sensitive topics?  
Yes

## Section C: Summary of research

## 1. Aims & Objectives

The overall aim of the study is to investigate the role of online discussion forums on type 2 diabetes patients'™ treatment management and decision making. More specifically, the objectives of the research are:

- To better understand the effect of online support groups (OSGs) on patients'™ empowerment by carrying out an in-depth, mixed-method study.
- To describe how patients process the information they receive on OSGs and turn it into actions.
- To identify information needs of patients with type 2 diabetes.
- To explore how trust is being developed in online communities and how it leads patients to take actions based on the information they found on forums.
- To investigate the impacts of these empowerment implications on patients'™ health.
- To identify patients'™ characteristics of the studied online community regarding empowerment.

## 2. Methodology

The study will be a two-arm study. The researcher will first collect and analyse posts from selected diabetes online support groups. Then based on the results of the analysis, he will conduct either an online questionnaire or interviews with current or former OSGs users. Therefore, this application is for collecting and analysing online posts and the researcher will apply for another ethics approval once it is clear which second method will be used. The collected data will be analysed by the researcher by using thematic analysis and/or content analysis and descriptive statistics.

Although selected support groups will be public, groups'™ administrators/moderators will be contacted to request permission to analyse the posts. If the administrators/moderators do not agree, other support groups will be contacted. It is important to note that the researcher will pay attention to the local culture of the online support group and the possibility of being perceived as intruding upon the privacy of members who may feel unobserved and despite being in a public space (as illustrated in the University of Sheffield Ethics policy). Members of the groups will be anonymised, and will not be identified explicitly or by implication in the research. Also, any quotes from the collected posts in the research will be paraphrased to ensure that members of OSGs cannot be traced via search engines.

Threads that are posted in an agreed specific time period and serve the aim and objectives of the research will be selected. The analysis of the posts will help the researcher to plan the next stage of the research by giving insights about whether interviews or questionnaire is more appropriate in answering the research questions. Analysing posts first also helps the researcher to design and frame questions for the /interviews/questionnaire.

The analysis of the posts will follow Marshall and Rossman (1999) six-phase guideline: (1) organise the data, (2) generate categories or themes, (3) code the data, (4) test emergent understandings of the data, (5) search for alternative explanations of the data and (6) write-up the data analysis.

Selection criteria for OSGs will be explained in the Potential Participants Section.

## 3. Personal Safety

Raises personal safety issues? No

Personal safety management

- not entered -

## Section D: About the participants

### 1. Potential Participants

During the end of the first year and the beginning of the second academic year, the investigator will search for as many diabetes online support groups that follows the following criteria:

- Written in English.
- Publicly available to read, in accordance with the The University of Sheffield's (n.d.) Ethics policy governing research Involving human participants, personal data and human tissue. Also, the groups should not ask for registration or ask permission to access members'™ posts. The researcher will examine the sites'™ privacy policy and other metadata for any active discouragement of researchers.
- Have online discussion forums about diabetes.
- Be active groups (e.g., 45 or more posts in the last three months).
- Focused on the UK. Although it is arduous to limit an online space in a specific country and ensure that all participants live in the UK, the researcher will ensure that the support group are directed to UK participants. There are many indications that might help the researcher to ensure that; such as the domain name (.uk), the terms and conditions (follow English law) or the 'œabout' section might indicate the geographical focus of the group.

### 2. Recruiting Potential Participants

Groups'™ administrators/moderators of relative OSGs will be contacted via the university email to request permission to analyse the posts. The administrators/moderators will be emailed a general overview of the research, its aim and objectives to allow them to understand the project and its goals. If the administrators/moderators do not agree, other support groups will be approached. If they do not response to the sent email, the researcher will contact them via a university landline (if there is a clear number to call on the website).

#### 2.1 Advertising methods

Will the study be advertised using the volunteer lists for staff or students maintained by CiCS? No

- not entered -

### 3. Consent

Will informed consent be obtained from the participants? (i.e. the proposed process) No

Due to the large number of OSGs members who might have been posting in the group for months or years, the researcher will not be able to contact them to obtain informed consent. However, the selected groups will be available to the public and will not require registration to access them. The researcher will consider only groups that have informed their users that the content users generate is publically available and can be used for research purposes (through the user agreement). As it is stated in the university'™s guidelines for researching social media:

As with all research involving observation of public space it is recognised that it is often infeasible and unnecessary to gain the consent of all that may be observed. If researchers are observing individuals in public places then unless consent is gained specific individuals should not be identified, explicitly or by implication, in any reporting of the research, other than public figures acting in their public capacity (as in reporting a speech by a named individual, for example). This aligns with recommendations in a number of social media research ethics guidelines. In such cases, if appropriate anonymisation is used then it may be appropriate to argue that consent is not required. However, explicit consent to use the OSG posts for the purpose of this research will be obtained from groups' administrators/moderators. They will be contacted to request permission to analyse the posts. Adequate information about the research will be provided to ensure that they fully understand the purpose of the study. As emphasised by The University of Sheffield's principles of consent, 'consent must be given freely and voluntarily and under no circumstances must direct coercion or indirect pressure be used to obtain a person's consent to participate in research' (p.1).

#### 4. Payment

Will financial/in kind payments be offered to participants? No

- not entered -

#### 5. Potential Harm to Participants

What is the potential for physical and/or psychological harm/distress to the participants?

Since the study is a desk-based research and participants are not directly contacted, there is a minimal risk of harms. However, the analysed material will be publically accessed and there is the risk that original posters can be identified by using search engines. There is also the risk of data being accessed by unauthorised users.

How will this be managed to ensure appropriate protection and well-being of the participants?

The privacy of online support group members has been highly and carefully considered in the research. Members will be anonymised and their posts will be paraphrased when they are mentioned in the research so they original posters cannot be identified through the use of search engines. Data will be protected by password to ensure only the researcher and supervisors can only access it (more details about data protection in the next section).

### Section E: About the data

#### 1. Data Confidentiality Measures

To ensure the confidentiality and security of the data, the researcher will anonymise usernames of posters (e.g., names, IDs) so they cannot be identified. They will be removed and replaced with pseudonym or code. Also, any other information that might lead to the identification of a user (e.g, location, membership number, length of being a member) will be removed. All of the content will be stored in a password-protected server only accessible by the researcher. As mentioned before, when referring/quoting any post, the original post will be paraphrased. OSGs administrators will be fully informed of how the posts will be stored, analysed, used and disclosed.

## 2. Data Storage

In accordance to the university policies, the data will be stored in a password-protected medium. The data will be stored in a secure networked drive and in the researcher's University of Sheffield Google Drive account. The data will be accessed only by the researcher and his supervisors (Abdulaziz Almanea, Prof. Peter Bath and Dr. Laura Sbaffi). The data will be analysed by the researcher. The use of paper copies will be avoided unless essential and will be kept in a locked storage in the Information School. The papers will be destroyed as soon as no longer needed.

After successful completion of the Ph.D., the data will be passed to the supervisors to either keep it stored in the same secured networked drive or transfer it to another secure drive (within the university policies) so it can be used for future researches and publications.

## Section F: Supporting documentation

### Information & Consent

Participant information sheets relevant to project?

No

Consent forms relevant to project?

No

### Additional Documentation

None

### External Documentation

- not entered -

## Official notes

- not entered -

## Section G: Declaration

Signed by:

Abdulaziz Almanea

Date signed:

Thu 26 October 2017 at 14:43



Downloaded: 26/11/2017  
Approved: 17/11/2017

Abdulaziz Almanea  
Registration number: 160262920  
Information School  
Programme: PhD

Dear Abdulaziz

**PROJECT TITLE:** The Role of Online Support Groups in Empowering Type 2 Diabetes Patients  
**APPLICATION:** Reference Number 016206

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 17/11/2017 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 016206 (dated 26/10/2017).

The following optional amendments were suggested:

*Your ethics application has been approved, but please take note of the suggested amendments listed in the main body of the application.*

If during the course of the project you need to [deviate significantly from the above-approved documentation](#) please inform me since written approval will be required.

Yours sincerely

Daniel Rose  
Ethics Administrator  
Information School





The  
University  
Of  
Sheffield.

## The Role of Online Support Groups in Empowering People with Type 2 Diabetes in the United Kingdom

The purpose of this study is to provide a deep understanding about the role of online support groups (OSGs) on patient empowerment among patients with Type 2 Diabetes in the UK. The study will provide insights about factors that affect patient empowerment and the treatment decisions for patients, the impact of empowerment on patients' decisions and health. These decisions might be related to:

- Patient-doctor relationship: changing doctor, seeking another medical opinion from other doctors, questioning doctor's knowledge;
- Treatment decisions: trying new medicines, changing drug dose, looking for alternative medicine;
- Lifestyle and diet-related decisions: eating, drinking and sleeping habits, sports.

### What is the aim and objectives of the research?

The overall aim of this study is to investigate the role of OSGs on treatment, management and decision making for people with Type 2 diabetes. More specifically, the research objectives are:

- To develop a better understanding of the effect of OSGs on patient empowerment by carrying out an in-depth multi-method study.
- To describe how patients utilise the information they receive on OSGs and turn it into actions.
- To identify the information needs of patients with Type 2 diabetes.
- To explore how trust is developed in online communities and how it leads patients to take actions based on the information they find in OSGs.
- To investigate the impact of OSGs on patients' perception of their health.

### Who are the researchers?

The lead researcher of this study is [Aziz Almanea](#), who is a second-year PhD student in the Health Informatics Research Group, Information School, University of Sheffield.

The study is supervised by [Prof. Peter Bath](#) and [Dr. Laura Sbaffi](#) who are Professor and Lecturer of Health Informatics in the School.

Further information about the researchers:

Aziz Almanea: <https://www.sheffield.ac.uk/is/pgr/students/almanea>

Prof. Peter Bath: <https://www.sheffield.ac.uk/is/staff/bath>

Dr. Laura Sbaffi: <https://www.sheffield.ac.uk/is/staff/sbaffi>

### Who will be participating?

The research will be approaching a number of diabetes online support groups in the UK.

**What will you be asked to do?**

We ask you to allow the lead researcher to collect and analyse publically-accessible past posts on your website.

**What will the researcher do with the data?**

The data will be used in the researcher's PhD thesis and future publications. Only selected posts that serve the research objectives will be downloaded and analysed. Any identifying information (e.g., username, user ID, geographical location...etc.) will be removed from the original posts. The data then will be thematically analysed.

**What is the potential risks to the participants?**

The collected and analysed material will be publically accessed and there is the risk that original posters can be identified by using search engines. The privacy of online support group members has been highly and carefully considered in the research. Members will be anonymised and their posts will be paraphrased when they are mentioned in the research so they original posters cannot be identified through the use of search engines. Data will be protected by password to ensure only the researcher and supervisors can only access it.

**How the data is going to be stored?**

All data will be held securely in firewall and password protected university drives.

**Ethical approval**

The research has obtained an ethical approval from the [University of Sheffield Ethics Committee](#) (attached).

**What will happen to the results of the research project?**

The analysed anonymous information will be used in the PhD thesis and disseminated at conferences and via articles. If your permission is obtained, the anonymised posts will be kept by the University of Sheffield for use in future research by the research team only.

The research project is estimated to complete approximately around Spring 2020. If you would like a summary of the results, please let the lead researcher know.

**Interested?**

If you are happy to allow the researcher to proceed, please email Aziz Almanea at [AMAlmanea1@sheffield.ac.uk](mailto:AMAlmanea1@sheffield.ac.uk). If you have any question, please do not hesitate to contact the researcher.

**Thank you very much for your time!**

Appendix 4 Ethics application for the Interview Study



## Application 021299

Section A: Applicant details
Date application started: Wed 20 June 2018 at 17:17
First name: Abdulaziz
Last name: Almanea
Email: amalmanea1@sheffield.ac.uk
Programme name: PhD Information Studies
Module name: PhD Information Studies
Last updated: 29/08/2018
Department: Information School
Applying as: Postgraduate research
Research project title: The Role of Online Support Groups in Empowering Type 2 Diabetes Patients
Has your research project undergone academic review, in accordance with the appropriate process? Yes
Similar applications: 016206

Section B: Basic information				
Supervisor				
<table><thead><tr><th>Name</th><th>Email</th></tr></thead><tbody><tr><td>Peter Bath</td><td>p.a.bath@sheffield.ac.uk</td></tr></tbody></table>	Name	Email	Peter Bath	p.a.bath@sheffield.ac.uk
Name	Email			
Peter Bath	p.a.bath@sheffield.ac.uk			
Proposed project duration				
Start date (of data collection): Wed 1 August 2018				
Anticipated end date (of project) Sun 31 January 2021				
3: Project code (where applicable)				
Project code - not entered -				

#### Suitability

Takes place outside UK?  
No

Involves NHS?  
No

Health and/or social care human-interventional study?  
No

ESRC funded?  
No

Likely to lead to publication in a peer-reviewed journal?  
Yes

Led by another UK institution?  
No

Involves human tissue?  
No

Clinical trial or a medical device study?  
No

Involves social care services provided by a local authority?  
No

Involves adults who lack the capacity to consent?  
No

Involves research on groups that are on the Home Office list of 'Proscribed terrorist groups or organisations'?  
No

#### Indicators of risk

Involves potentially vulnerable participants?  
Yes  
Involves potentially highly sensitive topics?  
Yes

### Section C: Summary of research

#### 1. Aims & Objectives

The overall aim of this study is to investigate the influence of online support groups (OSGs) on patient empowerment for people with Type 2 diabetes. More specifically, the research objectives are:

- To understand the information needs and information behaviours of patients with Type 2 diabetes through their use of OSGs.
- To develop a better understanding of how the use of OSGs by people with Type 2 diabetes can support patient empowerment (specifically in relation to patient engagement, their being informed, collaborative, committed and able to cope with uncertainty).
- To investigate how different contextual and interpersonal factors, as well as personal resources, affect patient empowerment among people with Type 2 diabetes who use OSGs.
- To describe how patients with Type 2 diabetes utilise the information they receive on OSGs and how this influences their health behaviours.

#### 2. Methodology

The study is a two-arm study. The first stage involved collecting and thematically analysing posts from selected diabetes online support groups. The first stage was approved by the University of Sheffield Research Ethics Committee (application no. 016206), and is in progress.

The second stage will involve conducting semi-structured interviews with current or former OSGs users; therefore, this application is for the second stage of the research.

The interview data will be analysed by the researcher by using thematic analysis. The sample characteristics will be analysed using descriptive statistics.

Interviewees will be recruited through a call to participate in the study which will be posted in the OSGs. OSGs' administrators/moderators on 3 sites have agreed to support the study and allow the researcher to post the call for participation in their OSGs.

Selection criteria for OSGs is explained in the Potential Participants Section below.

### 3. Personal Safety

Have you completed your departmental risk assessment procedures, if appropriate?

- not entered -

Raises personal safety issues?

No

- not entered -

## Section D: About the participants

### 1. Potential Participants

Potential participants will be:

- Adults (over the age of 18).
- Type 2 diabetes patient.
- Current or former OSGs users (not friends or family members of a patient). They must have used the OSG for at least for two months, so they have some experience of the support group.
- Posters (those who post on the online groups) or lurkers (those who do not post).
- Speak English.
- Have lived the past 6 months in the UK. The theoretical framework used in the study emphasises the influence of environmental factors in empowering patients. Therefore, environmental factors, such as healthcare service providers, are considered in the study. Since the geographical focus of the study is on the UK, participants are expected to have lived and experienced environmental factors recently in the UK.

Participants will be recruited based on a first come first served basis. The variety of representations of the participants will be reviewed and ensured that they are not biased.

### 2. Recruiting Potential Participants

Three diabetes OSGs have agreed to participate in the first stage of the study. They also showed interest in participating in the second phase when it gets the required ethical approval.

After the ethical approval is obtained, the OSGs moderators will be contacted to arrange a call for participation in the study to be posted in the appropriate section in the OSGs. The post will include a description of the research, its aim and objectives. It will also contain a link to a Google form (created using the researcher's official account) where they can fill in their basic information so they can be contacted by the researcher. Once they fill in the form, the researcher will email a number of them with an invitation to participate with the consent information sheet attached to the email and their preferences regarding the interview time, method (e.g., in-person, Skype) and location.

#### 2.1. Advertising methods

Will the study be advertised using the volunteer lists for staff or students maintained by CICS? No

- not entered -

### 3. Consent

Will informed consent be obtained from the participants? (i.e. the proposed process) Yes

The consent information sheet (attached in this application) will be attached in the recruitment post. It also will be sent to all potential participants via email once the researcher first emails them. Potential participants will be invited to ask further questions via their preferred medium of email, phone or Skype. Written consent will be requested before the interview commences (either emailed or to be taken in person before the interview).

### 4. Payment



Will financial/in kind payments be offered to participants? Yes

Participants will be offered travel expenses, to ensure access to the study for people who are economically disadvantaged. This will be reimbursed via cheque.

#### 5. Potential Harm to Participants

What is the potential for physical and/or psychological harm/distress to the participants?

There is always a risk with face-to-face interviews with strangers. Thus, it is important to meet them in a public space such as the university or a coffee shop near it. The preferred option would be to meet them in any available meeting room in the Information School. If the interviewee does not prefer to come to the university, the researcher will contact a public library that is preferred to the interviewee to reserve a meeting room with adequate privacy. The researcher will ensure that the building is disabled-friendly. People with mobility or hearing issues may prefer online support group than face to face meeting since it is easier for them to communicate; therefore, it is important to ensure that the building is friendly for people with disabilities in case any of the participants has a difficulty.

Since the interviewees are people with diabetes, the researcher will be aware of the first aid instructions for diabetes patients and be prepared to seek medical help in the unlikely event that any of the participants become unconscious or have any medical difficulty during the interview.

The researcher will offer to pause or stop the interview if the interviewee gets emotional (e.g., sad, upset) when talking about their health condition or experience.

For participants who are not able to travel to Sheffield, they will be interviewed via phone or Skype. They will be reached through a university landline or a dedicated Skype account for the purpose of this research only.

How will this be managed to ensure appropriate protection and well-being of the participants?

Please see the previous section (5.1).

### Section E: About the data

#### 1. Data Processing

Will you be processing (i.e. collecting, recording, storing, or otherwise using) personal data as part of this project? (Personal data is any information relating to an identified or identifiable living person).

Yes

Which organisation(s) will act as Data Controller?

University of Sheffield only

#### 2. Legal basis for processing of personal data

The University considers that for the vast majority of research, 'a task in the public interest' (6(1)(e)) will be the most appropriate legal basis. If, following discussion with the UREC, you wish to use an alternative legal basis, please provide details of the legal basis, and the reasons for applying it, below:

- *not entered* -

Will you be processing (i.e. collecting, recording, storing, or otherwise using) 'Special Category' personal data?

Yes

The University considers the most appropriate condition to be that 'processing is necessary for archiving purposes in the public interest, scientific research purposes or statistical purposes' (9(2)(j)). If, following discussion with the UREC, you wish to use an alternative condition, please provide details of the condition, and the reasons for applying it, below:

processing is necessary for archiving purposes in the public interest, scientific research purposes or statistical purposes' (9(2)(j)).

#### 3. Data Confidentiality

What measures will be put in place to ensure confidentiality of personal data, where appropriate?

Contact details and other basic information will be collected via using Google Forms and safely stored in Google Drive. All information obtained from participants will be carefully anonymised when the interviews are transcribed, and names and any details that could identify you or other people will be removed. In the write up of my findings, a pseudonym will be given to each participant and will not identify the names that they have mentioned (e.g., GP name, organisation names). Only the researcher, supervisors and the IT support team will have access to that.

#### 4. Data Storage and Security

In general terms, who will have access to the data generated at each stage of the research, and in what form

The data will be stored in a secure networked drive and in the researcher's University of Sheffield Google Drive account. The data will be accessed only by the researcher and his supervisors (Abdulaziz Almanea, Prof. Peter Bath and Dr. Laura Sbaffi) and the IT support staff.

A transcription service, which has been previously used and recommended by the School, might be used to transcribe the interviews. The data will be anonymised and a confidentiality agreement will be signed by the transcriber prior to any data transfer to ensure the confidentiality of the data.

What steps will be taken to ensure the security of data processed during the project, including any identifiable personal data, other than those already described earlier in this form?

The use of identifiable personal information in the research will be reduced as much as possible, for example:

- Google Forms will be used to collect potential participants information. Using Google Forms will store the data directly and securely on Google Drive.

- Addresses will not be collected but just city/region names.

Will all identifiable personal data be destroyed once the project has ended?

Yes

Please outline when this will take place (this should take into account regulatory and funder requirements).

All personal data will be destroyed after approximately 6 months after successful completion of the degree.

#### Section F: Supporting documentation

##### Information & Consent

Participant information sheets relevant to project?

No

Consent forms relevant to project?

Yes

Document 1047768 (Version 2)

[All versions](#)

##### Additional Documentation

##### External Documentation

- not entered -

#### Section G: Declaration

Signed by:

Abdulaziz Almanea

Date signed:

Mon 30 July 2018 at 17:37

#### Official notes

- not entered -

## Appendix 5 Ethics approval letter for the Interview Study



Downloaded: 28/09/2018  
Approved: 29/08/2018

Abdulaziz Almanea  
Registration number: 160262920  
Information School  
Programme: PhD Information Studies

Dear Abdulaziz

**PROJECT TITLE:** The Role of Online Support Groups in Empowering Type 2 Diabetes Patients  
**APPLICATION:** Reference Number 021299

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 29/08/2018 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 021299 (dated 30/07/2018).
- Participant consent form 1047768 version 2 (30/07/2018).

The following optional amendments were suggested:

*Please correct the typo in Section 3. Data Confidentiality as mentioned above.*

If during the course of the project you need to [deviate significantly from the above-approved documentation](#) please inform me since written approval will be required.

Yours sincerely

Daniel Rose  
Ethics Administrator  
Information School



The University of Sheffield  
Information School



The  
University  
Of  
Sheffield.

The Role of Online Support Groups in  
Empowering People with Type 2 Diabetes  
in the United Kingdom.

#### Researchers

The lead researcher of this study is Aziz Almanea (amalmanea1@sheffield.ac.uk), who is a second-year PhD student in the Health Informatics Research Group, Information School, University of Sheffield. The study is supervised by Prof. Peter Bath (p.a.bath@sheffield.ac.uk) and Dr. Laura Sbaffi (l.sbaffi@sheffield.ac.uk) who are Professor and Lecturer of Health Informatics in the School respectively.

Further information about the researchers can be found:

Aziz Almanea: <https://www.sheffield.ac.uk/is/pgr/students/almanea>

Prof. Peter Bath: <https://www.sheffield.ac.uk/is/staff/bath>

Dr. Laura Sbaffi: <https://www.sheffield.ac.uk/is/staff/sbaffi>

#### Purpose of the research

The overall aim of this study is to investigate how people with Type 2 Diabetes use online support groups/online health forums to support their condition.

#### Who will be participating?

I am inviting adults (over the age of 18) who are diagnosed with Type 2 diabetes and have used (or are still using) online support groups (OSGs) (both posting or just reading) to manage their diabetes for at least 6 months. Participants must speak English and have lived in the UK for the past 6 months.

#### What will you be asked to do?

If you are interested in taking part in the study, I would like to talk with you about your experience in using online support forums to manage your Type 2 diabetes. We expect that most interviews will last between 40 to 60 minutes but this is flexible. Interviews can be either in person, via Skype, or by phone; whichever you prefer. The lead researcher, who will carry out the interviews, is based in Sheffield and is willing to travel to interview you. However, if you need to incur into travel expenses to take part in the study, you will be reimbursed reasonable travel expenses (from within the UK) by cheque. If you think you need to pay any travel expenses to participate in the study, please let the lead researcher know before the interview.

You have the right to refuse to participate in the study as well as to refuse to answer any of the questions. You also have the right to withdraw from the research at any time without having to give a reason. These rights, however, cannot be extended after the data has been anonymised, analysed or published.

#### What are the potential risks of participating?

The risks of participating are the same as those experienced in everyday life.

#### What data will I collect?

I will audio record the interviews, and take notes on paper to help me when analysing the interview. I will ask you for information about the frequency and duration of your using the online support group,

education level, cultural background, age group and geographical location. This will help me to understand how these might influence the use of the online support forum.

#### **What will I do with the data?**

In accordance to the university policies, the data will be stored in a password-protected system. The data will be stored in a secure networked drive and in the researcher's University of Sheffield Google Drive account. The data also will be encrypted and it will be accessed only by the researcher and his supervisors (Abdulaziz Almanea, Prof. Peter Bath and Dr. Laura Sbaffi). The data will be thematically analysed by the lead researcher to give a rich description of the collected data.

The use of paper copies will be avoided unless essential and will be kept in a locked storage in the Information School. The papers will be destroyed as soon as they are no longer needed. If you give us permission, we would like to retain the transcriptions after the completion of the project for use in future by the research team. The anonymised data will be passed to the supervisors to either keep it stored in the same secured networked drive or transfer it to another secure drive (within the university policies) so it can be used for future research.

Your completed consent form will be held in securely locked storage in the Information School and will be confidentially destroyed at the end of the project.

A transcription service might be used to transcribe the interviews. The data will be anonymised and a confidentiality agreement will be signed by the transcriber prior to any data transfer to ensure the confidentiality of the data.

#### **Will your participation be confidential?**

The privacy and data confidentiality of all participants are very important for the research team. All information you give us will be carefully anonymised when the interviews are transcribed, and names and any details that could identify you or other people will be removed. In the write-up of my findings I will give you a pseudonym and any names that you have mentioned (e.g., GP name, organisation names, place names, etc.) will be anonymised.

#### **What will happen to the results of the research project?**

The anonymised data will be used in the researcher's PhD thesis, which will be publicly available, and in future research publications. It is also possible that the anonymised findings will be presented at conferences.

A summary of the results will be sent to the participants. After the completion of the Ph.D. thesis (which is anticipated to be at the beginning of 2020 for this study), the Ph.D. thesis will be published in the White Rose System [<http://etheses.whiterose.ac.uk>].

#### **What is the legal basis for processing your personal data?**

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is 'a task in the public interest'.

As we will be collecting some data that is defined in the legislation as more sensitive (information about your health), we also need to let you know that we are applying an additional condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

#### Declaration of consent

- I confirm that I have read and understand the description of the research project, and that I have had an opportunity to ask questions about the project.
- I understand that my participation is voluntary and that I am free to withdraw at **any time/before 01/02/2019** without any negative consequences.
- I understand that if I withdraw I can request for the data I have already provided to be deleted, however this might not be possible if the data has already been anonymised or findings published.
- I understand that I may decline to answer any particular question or questions, or to do any of the activities.
- I understand that my responses will be kept strictly confidential, that my name or identity will not be linked to any research materials, and that I will not be identified or identifiable in any report or reports that result from the research, unless I have agreed otherwise.
- I give permission for all the research team members to have access to my responses.
- I give permission for the research team to re-use my data for future research as specified above.
- I agree to take part in the research project as described above.

Participant Name (Please print)

Participant Signature

Researcher Name (Please print)

Researcher Signature

Date

**Note: Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), can be found in the University's Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>. If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, please contact Dr Jo Bates, Research Ethics Coordinator, Information School, The University of Sheffield ([ischool\\_ethics@sheffield.ac.uk](mailto:ischool_ethics@sheffield.ac.uk)).**

<b>Starting the interview</b>	
<ul style="list-style-type: none"> <li>• Thanking the participant for taking part in the study.</li> <li>• Introducing the researcher and research team.</li> <li>• Introducing the research topic.</li> <li>• Reading the information sheet (which has been sent to them before the interview) and making sure that they read it.</li> <li>• Ensuring the confidentiality and security of the environment.</li> <li>• Reminding the participant about their right to withdraw/ stop and continue at any time and not answer any of the questions.</li> <li>• Requesting participant’s verbal consent to take part in the study.</li> <li>• Asking for participant’s permission to record the interview.</li> <li>• Starting the Diabetes and OSG activity questionnaire (Table 5.4).</li> <li>• Starting the interview questions with the below warm up questions.</li> </ul>	
<b>Warm up questions</b>	
Question	Follow-up Questions
To start with, what were your first thoughts, your initial when you were first diagnosed?	
After the diagnosis, were you given any educational courses or information to help you manage your diabetes?	<ul style="list-style-type: none"> <li>a) Did you find them useful?</li> <li>b) Did you use other sources to learn about diabetes (e.g., the Internet, friends/family members, media)?</li> </ul>
<b>Part One</b>	
<i>The use of the forum as a source of information/support. Focus on information needs, behaviours and utilisation.</i>	
2. Can you please tell me about your experience with the forum?	<ul style="list-style-type: none"> <li>a. How did you find it originally? What were you looking for?</li> <li>b. What made you continue using it (Why do you stay with it/like it)?</li> <li>c. Do you write or read there or both?</li> <li>d. Did you observe or post straightaway?</li> <li>e. What about your first post, do you remember what was it about?</li> <li>f. How long have you used it?</li> <li>g. How often do you use it in an average week?</li> <li>h. How do you use it? Are there particular sections on the forum that you use and like more than others?</li> <li>i. What about other people in the forum? Is it usually the same people you contact on the forum?</li> </ul>

	<p>j. Apart from the forums, do you use the site as a whole? Do you read other parts of it, for example, the information pages?</p>
<p>3. What types of advice you were looking for in the forum (e.g. information about diet, medications, doctors)?</p>	<p>a. How did the forum help you find what you were looking for?  b. Can you please tell me about an instance where you needed the forum?  c. Did the type of advice you were looking for in the forum change overtime?</p>
<p>4. To what extent would you trust the advice you found in the forum?</p>	<p>a. Did you check other sources for the same advice to confirm it (corroborate it) (e.g. other websites, doctor, books)?  b. Did you discuss it with your GP/HCPs?  c. Do you find the experience of members on the forum valuable?</p>
<p>5. Now, can you please tell me more about the advice you found on the forum, have you ever put a piece of advice given by the forum into practice?</p>	<p>a. What was it about?  b. Did you read/learn about it more elsewhere?  c. When you followed that advice, did you go back to the forum to read/learn more about it?  d. Did the forum help you to overcome any difficulty in managing your diabetes?  e. If yes, what was the difficulty/challenge?</p>
<p>6. How do you think the information in the forum helped you to manage your diabetes?</p>	<p>a) How it helped?  b) Did it help you to do anything differently, e.g., eat healthier food or stop eating any unhealthy food?  c) Did the forum help you to keep this up over time?</p>
<p><b>Part Two</b>  <i>The influence of social/ environmental factors.</i>  <i>Focus on social/environmental factors that affect the patient empowerment.</i></p>	
<p>Now I would like to ask you about your management of your diabetes, how do you manage your diabetes/ keep it in control?</p>	<p>a) Is it easy to manage? How do you do that?  b) How do you think diabetes should be managed?  c) Where would you say your ideas came from? Did the forum have an influence?</p>

<p>8- Do you feel that your GP is helping you in managing your diabetes?</p>	<p>a. Have you discussed the information you found in the forum with your GP? How did the discussion go?</p>
<p><b>Part Three</b> <i>Conclusion</i></p>	
<p>Is there anything else you would like to share to help me understand your experience of using the forum to manage your diabetes?</p>	
<p>Are you happy to be contacted with a summary of the findings?</p>	
<p><b>Ending the interview</b></p>	
<ul style="list-style-type: none"> <li>• Inform the participant what will happen next and leave a copy of the Information Sheet with him/her.</li> <li>• Thank them again for their time.</li> </ul>	





## **How Online Support Groups can help people with Type 2 Diabetes in the United Kingdom**

### **Summary of Findings**

The aim of this study was to develop a better understanding of how online support groups can help patients with Type 2 Diabetes in the UK. This report presents some of the findings from the study. I hope you find it an accurate account of what we discussed.

Please let me know if there is anything you don't agree with in the findings or if you want to change or add anything. You can contact me, Aziz Almana, at [AMAlmana1@sheffield.ac.uk](mailto:AMAlmana1@sheffield.ac.uk).

- Being diagnosed with Type 2 Diabetes (T2D) was a negative experience for most people. However, a few were less emotionally affected either because they were expecting it or did not fully understand it.
- Some people started searching for information before they were diagnosed. Some of them found online forums and joined them.
- Some participants received limited or no information when they got their diagnosis.
- At the first meeting with doctors/ diabetes nurses (after their diagnosis), most people received general information about Diabetes including a leaflet about the Eat Well Plate.
- At this meeting, some participants got the impression from their doctors/nurses that Diabetes is a progressive condition and people can do little to stop the progression.
- Some people were invited to attend information sessions (i.e., DESMOND course). Few people attended this.
- Some people found the course useful and it provided basic information about Diabetes, others found it useless as it provided limited choices and they were not allowed to discuss of some approaches and techniques to control diabetes (e.g., self-monitoring of blood glucose or low carb diet).
- Some people followed the official information/ treatment provided to them by their doctors/nurses for a few months/years. After that, they felt that they did not get the health results they wanted.
- Others, however, went searching online for more information about Diabetes and how to deal with it. Whilst searching online, many people found diabetes forums and joined them.
- Some people found different forums and joined the ones that provided new information (i.e., alternative approaches to manage T2D).

- Many people spent time reading in the forum before posting. Their first posts were about general questions to understand the condition and available treatment options.
- People accessed and used the forum differently. Some people used the forums only to find information whereas others used them to get emotional support and socialise with other people.
- The forum as an informative source of information. The experience of other members helped people to learn about the condition and practical tips to cope with it. The forum introduced many people to new information and approaches to treatment, such as the low carb diet.
- Some people discussed this new information and approaches with their doctors/nurses who mostly did not agree nor support them. This created tension between many people and their doctors/nurses and had a negative effect on their relationship.
- People varied in how much they trusted and checked the information they found in the forum. Some double-checked the information by searching about it online or checking its original source. Others saw how many members on the forum agreed with that advice and judged it based on that. Few believed other members that achieved good health status and could manage the condition more effectively.
- Most people cared most about whether a given treatment approach worked for them or not. It was not important if that approach was advised by their doctors/ nurses or not.
- When most people learned about something on the forum and wanted to apply it, they started applying it step-by-step to see how their body reacted to it.
- A number of people explained that their engagement in the forums helped them realise that Diabetes is their condition and they therefore need to manage the condition actively (e.g., they have to change some habits).
- Some people felt that they wanted to help others. They were therefore active in the forum to help new members and they also tried to improve the information provided to people with Diabetes.
- Some people kept using the forum to stay focused on managing their Diabetes, to provide information and to share their experience with other members and/or to stay connected with the community.

Thank you again for participating in the study and for reviewing this summary. If you have any questions or comments, please do not hesitate to contact me, Aziz Almanea, at [AMAlmanea1@sheffield.ac.uk](mailto:AMAlmanea1@sheffield.ac.uk).