Diabetic patient experiences of public and government messaging and help-seeking during the COVID-19 pandemic

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ABSTRACT

Research indicates that the COVID-19 pandemic has had far-reaching consequences on the global population, impacting on both mental and physical health. Despite the increased risk of severe illness and death from COVID-19, there is a paucity of research exploring the experiences of individuals with underlying health conditions during the pandemic, particularly in relation to government messaging and its impact on help-seeking behaviours. This thesis seeks to address these gaps by focusing on the experiences of people living with Type 2 diabetes during the COVID-19 pandemic in the UK.

Informed by a critical realist epistemology, this qualitative study employs semi-structured interviews with 13 participants to explore how government and public health messaging was experienced and the resultant impact on help-seeking behaviours. Thematic analysis revealed three main themes: 'Diabetes Identity,' 'Becoming [In]visible' and 'Going it Alone.'

Participants reported experiences of stigmatisation and feelings of shame as a consequence of messaging, along with the psychological impact of losing both social and healthcare support. They also described challenges in grappling with being positioned as 'vulnerable' and the poor differentiation with the use of this label, as well as issues around self-disclosure and a renegotiation of their relationship with their diabetes.

Recommendations for further research and improvements to government policy and guidelines are provided to better address the importance of considering the unique experiences and challenges faced by individuals with pre-existing health conditions, as well as the need for more inclusive and sensitive public health messaging to minimise stigmatisation and promote help-seeking behaviours.

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LIST OF ABBREVIATIONS

Below is a list of common abbreviations used throughout the research

NHS - National Health Service
WHO - World Health Organisation
T1DM - Type 1 Diabetes Mellitus
T2DM - Type 2 Diabetes Mellitus
PwD - People with Diabetes
PwT2DM - People with Type 2 Diabetes Mellitus

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Figure 1. Thematic Map

1. INTRODUCTION

1.1. Chapter Overview

The chapter begins with an overview of diabetes and its categorisation and prevalence. Following this, key aspects of the relationship between diabetes and mental health are discussed before examining the emerging literature on the impact of COVID-19 on individuals with diabetes and its relationship to help-seeking. An argument, from the literature, will be presented that demonstrates that individuals with diabetes navigate stigmatisation and experience shame related to their condition, which can exacerbate the emotional and mental health implications of living through the COVID-19 pandemic. Moreover, individuals with diabetes are susceptible to diabetes distress, which can be significantly amplified by feelings of shame related to the pandemic, resulting in potential barriers to accessing help. A literature review demonstrates the current research gaps in the context of the current global COVID-19 pandemic before offering a rationale for the proposed study and the research questions to be addressed.

1.2. Diabetes Mellitus

1.2.1. Pathogenesis, correlates and symptoms

Diabetes Mellitus describes a cluster of metabolic diseases that are characterised by hyperglycaemia that result from impairments in the secretion of insulin, insulin action or a combination of both (American Diabetes Association, 2014). Chronic hyperglycaemia has been linked to the failure of organs including the kidneys, eyes, blood vessels and heart (Chatterjee et al., 2017) with diabetes-related chronic hyperglycaemia being associated with the long-term damage to, or dysfunction of, these organs (Kreider et al., 2018). The development of diabetes involves various pathogenic processes, including the autoimmune destruction of β cells in the pancreas responsible for producing insulin, leading to insulin deficiency (Gillespie, 2006).

For people with diabetes (PwD), insulin secretion impairments and action defects frequently co-exist and there is a lack of clarity concerning which constitutes the primary cause of hyperglycaemia. Symptoms of hyperglycaemia include blurred vision, weight loss, polyuria, polydipsia and susceptibility to infections (Lim & Taylor, 2017). Uncontrolled diabetes can have life-threatening implications, including hyperglycaemia accompanied by ketoacidosis (Kreider et al., 2018). Diabetes can further induce long-term health complications such as renal failure (Nasri & Rafieian-Kopaei, 2015). The build-up of uremic toxins and increased levels of parathyroid hormones in PwD diagnosed with chronic renal failure can cause insulin resistance in tissues, especially skeletal muscle tissues (Nasri & Rafieian-Kopaei, 2015).

Other long-term complications of diabetes include peripheral neuropathy and the accompanying risk of foot ulcers (Jeffcoate & Harding, 2003) and amputations (Reiber & Ledoux, 2002). Diabetes is also associated with autonomic neuropathy and cardiovascular, gastrointestinal and genitourinary symptoms (American Diabetes Association, 2014; Maser et al., 2003). Autonomic neuropathy presents an increased risk for sexual dysfunction (Vinik & Erbas, 2001). In PwD, the incidence of atherosclerotic cardiovascular, peripheral arterial and cerebrovascular disease is higher (American Diabetes Association, 2014; Thiruvoipati et al., 2015) along with an increased risk of developing hypertension (Howard, 1987).

The wide variety of symptoms and the possible life-threatening outcomes of diabetes illustrates the magnitude of its effects on individuals living with the condition, as well as its widespread influence on the entire physiological system.

1.2.2. Etiopathogenetic Categories

Diabetes can be generally classified into two primary pathogenetic categories. The first type is associated with a total absence of insulin secretion, while the second type is connected to insulin resistance in the liver and muscles and/or an inadequate insulin secretion response (Forouhi & Wareham, 2014).

In 1980, the World Health Organisation (WHO) released the first widely recognised categorisation of diabetes, which divided the condition into two principal classes:

Type 1, also known as Insulin Dependent Diabetes Mellitus (IDDM) and Type 2, also known as Non-Insulin Dependent Diabetes Mellitus (NIDDM). However, the WHO revised this classification in 1985 by eliminating the terms Type 1 and Type 2 and retaining only the terms IDDM and NIDDM (WHO Study Group on Diabetes Mellitus & Organization, 1985).

This revised diabetes classification was limited in its scope due to the combining of the extent of insulin deficiency and pathogenesis. To address this issue, Kuzuya and Matsuda (1997) proposed a new classification in a highly influential report. The Kuzuya-Matsuda classification suggested that the cause and extent of insulin deficiency should be evaluated independently and integrated into the classification (Sreenivasamurthy, 2021). In response, the WHO revised its 1985 classification and adopted these proposals and the terms IDDM and NIDDM have been replaced with Type 1 diabetes mellitus (T1DM) and Type 2 diabetes mellitus (T2DM) respectively.

1.2.2.1. Type 1 Diabetes Mellitus

T1DM is predominantly characterised by an autoimmune aetiology and is often referred to as insulin-dependent or juvenile-onset diabetes, given its frequent manifestation in children and young adults. The pathogenesis of T1DM is primarily driven by the immune system erroneously targeting and destroying insulin-producing beta cells in the pancreas, consequently resulting in insulin deficiency (Atkinson & Eisenbarth, 2001). This autoimmune destruction is attributable to a complex interplay of genetic and environmental determinants. Notably, specific genes that are associated with the human leukocyte antigen (HLA) system have been identified as risk factors for T1DM development; however, the presence of these genes does not guarantee disease onset (Pociot & Lernmark, 2016). Additionally, research has implicated viral infections, such as enteroviruses, in eliciting autoimmune responses among genetically predisposed individuals. Other factors, including early exposure to cow's milk and vitamin D deficiency, have been proposed to influence T1DM development (Norris et al., 2020).

1.2.2.2. Type 2 Diabetes Mellitus

Often referred to as non-insulin-dependent or adult-onset diabetes, T2DM development hinges on several key factors. Insulin resistance emerges when cells become less responsive to insulin, compelling the pancreas to synthesise greater insulin quantities to maintain normal levels of glucose in the blood (Kahn & Flier, 2000). Over time, pancreatic insufficiency arises due to the unattainable demand for insulin, culminating in hyperglycemia. Numerous genes associated with an elevated risk of T2DM have been identified, which may influence insulin synthesis, action or glucose metabolism (American Diabetes Association, 2014). Nonetheless, genetic predisposition in isolation is considered to be inadequate alone for the disease to occur. Lifestyle factors such as obesity, sedentary lifestyles and poor dietary habits significantly contribute to insulin resistance and T2DM onset (Hu, 2011). Moreover, environmental factors including socioeconomic status, stress, and exposure to environmental pollutants have been implicated in T2DM development (Espelt et al., 2008) alongside the use of certain medications, like glucocorticoids (Kahn & Flier, 2000).

T1DM and T2DM differ in their pathophysiology, age of onset, genetic and environmental risk factors, symptoms, complications and treatment options. Understanding these differences is essential for effective management and prevention of diabetes-related complications.

1.2.3. Diabetes Prevalence and Incidence in the United Kingdom

In the United Kingdom (UK), approximately 4.9 million people have been diagnosed with diabetes, with an additional 900,000 people estimated to be living with the disease undiagnosed (Diabetes UK, 2020). It is predicted that diabetes prevalence is due to rise to 5.3 million people by 2025 (Diabetes UK, 2022). Approximately 90% of people diagnosed with diabetes in the UK live with T2DM, while 8% have T1DM (Diabetes UK, 2020). It is estimated that 3.5 million people in the UK have an increased risk for T2DM, which increases when a close family member is diagnosed with the disease (Diabetes UK, 2020). The prevalence of diabetes varies across different ethnic and cultural groups in the UK. According to the NHS Digital National Diabetes Audit for 2020-21 (National Diabetes Audit, 2022) people of Indian, Pakistani, Bangladeshi and Sri Lankan descent are up to six times more likely to develop T2DM than the White British population while people of Black African and Caribbean descent are up to three times more likely to develop T2DM than the White British population. In the UK, Black African-Caribbean populations have been consistently shown to display pronounced insulin resistance and higher rates of hypertension compared to other ethnic groups, even where abdominal obesity is not present (Diabetes UK, 2020). When compared to people from White British backgrounds, people from Black ethnic groups have a higher possibility of living with undiagnosed diabetes (National Diabetes Audit, 2022). Undiagnosed diabetes is particularly concerning due to those individuals not receiving appropriate treatment and management, which can lead to serious health complications. Ethnic disparities in undiagnosed diabetes are complex and likely to be related to a range of factors, including a lack of cultural inclusivity, discrimination and far-reaching social and economic structural inequalities creating barriers to accessing healthcare, in addition to potential genetic and lifestyle factors that may increase the risk of diabetes alongside these wider social determinants (Canedo et al., 2018).

1.2.4. Mental Health and Self-Care

While the applicability of Western mental health constructs across the globe is rightfully challenged (Mills & Fernando, 2014) their inclusion here serves to represent the existing literature and its biomedical bias accurately. It is essential to consider the potential issues arising from framing distress as a 'disorder' and the often-overlooked social determinants of poor physical and mental health. The legitimacy of mental health concepts, the inbuilt assumptions that Western notions of 'mental health' are universally applicable and the implications of disseminating these ideas as a form of 'knowledge' colonisation - leading to the loss of cultural diversity (Mills & Fernando, 2014) - should be contemplated throughout. The author acknowledges these underlying issues in the research on mental health and emotional wellbeing, particularly in conjunction with biomedical understandings of diseases like diabetes.

Over the past decade, there has been a growing emphasis on the importance of emotional wellbeing in diabetes care (Lloyd et al., 2020). Acknowledging the diverse experiences of PwD and their families, some common themes have emerged, such as adapting to a new diagnosis (Robinson et al., 2018), navigating self-care (e.g. managing medication and engaging in physical activities) (Ducat et al., 2014), addressing concerns about low blood sugar (Fisher et al., 2019) and exploring feelings surrounding insulin use (Holmes-Truscott et al., 2016).

1.2.4.1. Diabetes Distress

Diabetes distress concerns the emotional distress that is linked with the burdens, concerns and worries that emerge from managing the chronic and demanding disease of diabetes over a period of time (Fisher et al., 2019; Owens-Gary et al., 2019; Skinner et al., 2020). Thus, the concept of diabetes distress encapsulates the psychosocial adjustment challenges experienced by PwD (Skinner et al., 2020). It refers specifically to the negative affective or emotional experiences that occur in response to the demands of diabetes, despite the type of diabetes (Fisher et al., 2019). Of note, the literature on diabetes distress is skewed towards studies that examine adults with T2DM (Dunn et al., 1986; Fisher et al., 2007; Islam et al., 2015; Mathiesen et al., 2018; Tsujii et al., 2012). This may be due to a combination of factors, including T2DM being more commonly diagnosed in adults compared to T1DM emerging in childhood or adolescence, the range of potential co-morbidities including obesity, hypertension and dyslipidemia seen in T2DM and the increasing prevalence of T2DM in relation to the so-called ‘obesity epidemic’ which may draw greater attention of researchers, policymakers and healthcare providers (Sturt et al., 2015).

Studies show that diabetes distress is linked to gender in both those individuals with T1DM and T2DM (Perrin et al., 2017; Skinner et al., 2020). According to a systematic review conducted by Perrin et al. (2017), the higher prevalence of diabetes distress in T2DM women may be attributed to the increased presence of expressed emotional challenges due to different social norms for men compared to women. These social norms mean that men are less likely to admit to their distress to those in their immediate network or seek help because of a fear of being perceived as weak by healthcare providers. In both T1DM and T2DM, the likelihood of diabetes distress is higher in younger people (median split < 41 years) (Skinner et al., 2020). Difficulties with perceiving oneself as chronically unwell at a younger age, including a perceived lack of help from a PwD’s family or partner who may also experience a disjunction between young age and ill health, have been linked with increased diabetes distress in younger adults (Hessler et al., 2017; Schiøtz et al., 2012). Fisher et al. (2015) found that diabetes distress is more prevalent in racially minoritised groups as a consequence of socioeconomic disparities limiting access to supportive resources, a lack of culturally competent healthcare provision and experiences of discrimination in healthcare settings leading to a toll being taken on individuals' emotional wellbeing as a consequence.

Poor patient-provider communication has been linked to diabetes distress (Matthews et al., 2009). Patients perceive poor communication from physicians as a form of inattention which could lead to missed opportunities for treatment, or misdiagnosis, increasing patients' concern and emotional burden (Peimani et al., 2020). Poor communication between physicians and patients also prevents opportunities to discuss what is required in terms of self-care management, reducing the confidence of patients and introducing anxiety and an increased emotional burden. Dowell and colleagues (2018) performed a study which was aimed at observing the primary care interactions and communication between physicians and patients newly diagnosed with diabetes over time using video recordings of consultations. The study identified key points where miscommunication occurs and the resultant effects. The study found that while physicians had high levels of technical knowledge and communication skills, they focused on biomedical explanations of the disease and did not contextualise this within patients' lived experiences. They also repeated information that was not necessarily relevant to the needs of patients, culminating in missed opportunities to discuss the burden of treatment associated with the disease. Thus, poor communication meant few problem-solving opportunities were explored (Dowell et al., 2018).

1.2.4.1.1. The Impact of Diabetes Distress on Diabetes Self-Care and Management

Diabetes distress impacts diabetes self-management and related biomedical and behavioural outcomes compared to other emotional wellbeing indicators such as depression (Perrin et al., 2017). This distress adds to the burden of managing diabetes, leading to poorer self-care (Devarajooh & Chinna, 2017). People diagnosed with diabetes are required to follow dietary guidelines, adhere to medication regimes and increase physical activity (Brown et al., 2016). Those with T2DM may self-monitor glucose levels at home using glucometers (Polonsky et al., 2022), particularly newly diagnosed individuals struggling with metabolic control (Brown et al., 2016). Lifestyle changes can be challenging, as evidenced by unmet glycemic goals, rising obesity, low physical activity rates and difficulty sustaining weight loss (Powers et al., 2016).

A meta-analysis showed that diabetes distress significantly reduced dietary adherence and physical activity (Brown et al., 2016), with high stress levels predicting lower medication adherence. In contrast, motivational factors like coping and self-efficacy correlated with better medication adherence and glycaemic control (Brown et al., 2016). However, it is challenging to separate behavioural adherence from medical management effects in such studies (Glasgow et al., 2001).
Limited longitudinal cohort studies make it difficult to determine links between diabetes distress, poor self-care, complications or mortality (Skinner et al., 2020). However, research indicates that gender, patient education access and self-determination opportunities play roles in self-care for PwD in rural and diverse communities (Bell et al., 2006).

Self-determination interventions, in the form of computer assisted, patient-driven technology, have been shown to improve self-care for patients experiencing diabetes distress (Williams et al., 2007). Findings from the study by Williams and colleagues (2007) support the self-determination model (Deci & Ryan, 2012) by demonstrating that patient autonomy was supported as a result of a change in self-perceived competence resulting in greater adherence to treatment plans resulting in better glycaemic control. Besides self-determination theory, systemic and contextual factors contribute to individuals' challenges with diabetes with social determinants and systemic inequalities impacting upon self-care. Access to healthcare can be limited by economic status, location and service availability (Hill et al., 2013). Affordability of nutritious food, particularly in low-income areas, can hinder proper dietary management (Walker & Litchman, 2021). Social and cultural factors, such as family dynamics and cultural food norms, can influence individuals' ability to engage in lifestyle changes required to manage their diabetes (Weaver et al., 2014).

1.2.5. Shame

Shame is rooted in individuals' experience of having the negative aspects of themselves exposed (Gilbert & Irons, 2008). Specifically, shame is linked to *"the experience of the other feeling contempt or ridicule for various aspects of the self"* (Gilbert & Irons, 2009, p.197). External shame pertains to the manner in which attention and cognitive processing are oriented externally, taking into account the interplay between individual perception and the broader social context regarding others' thoughts about oneself. Internal shame involves directing attention and cognitive processing inward, toward our own emotions, individual traits and actions, while acknowledging the influence of social structures and definitions. Nevertheless, this focus remains rooted in a socially contextualised framework, as the focal point of internal shame addresses societal standards that differentiate between what is considered appealing and desirable versus what is deemed unappealing and undesirable, highlighting the complex interplay between individual experience and social context.

According to the biopsychosocial model of shame (Gilbert, 2006) shame arises from complex cognitive processes, which provide warning signals to individuals that they are being perceived negatively in the mind of others. The model adopts an integrative and evolutionary approach to illustrate how shame is derived from the innate attachment-seeking behaviours of humans, as well as their quest for group belonging and social acceptance (Baumeister & Leary, 1995; Bowlby, 1982; Gilbert, 1998). The quest to be valued by others in a social context, shapes brain maturation and the regulation of affect, creating feelings of connectedness and safeness and mitigating distress when threats are encountered (Cunha et al., 2012). Where individuals do not gain this social acceptance for example, evident through the experience of being ridiculed, criticised or abused, their emotion regulation is compromised, undermining the co-construction of favourable social roles which play a part in triggering threat-related responses (Cunha et al., 2012; Gilbert, 1998; Gilbert & Irons, 2008). Against this backdrop, shame emerges amidst a competition for social attractiveness which is the result of evolved cognitive abilities to process both self-related and social information (Cunha, Matos, Faria & Zagalo, 2012). As a result, shame functions as an ‘alert mechanism,’ indicating that an individual is unsuccessful in generating favourable emotions in others and consequently occupies a negative mental space in their perception (e.g., being perceived as insufficient or inadequate). This, in turn, places the individual at a heightened risk of experiencing rejection, exclusion, marginalisation, aggression or persecution (Cunha, Matos, Faria & Zagalo, 2012).

1.2.5.1. Shame and Diabetes

The biopsychosocial model of shame provides important insight into illness-related shame. In a study by Browne and colleagues (Browne et al., 2013), it was found that 84% of participants living with T2DM believed that T2DM was a highly stigmatised condition or reported personal experiences of stigmatisation. Stigmatisation involves being blamed by others for causing diabetes, experiencing negative stereotyping or experiencing discrimination (Browne et al., 2013). Researchers found that the stigmatisation of diabetes primarily emerges from the media, family, friends and healthcare professionals (Browne et al., 2013). The biopsychosocial model described above, illustrates how shame emerges in response to a lack of social approval. Archer (2014) argues that when diabetes patients are confronted about their high glucose values, they may experience feelings of anger - not as a result of feeling confronted - but due to a sense of failure concerning their own self-management. A corollary of negative judgments made by some health professionals is that failure in self-management may become linked to a sense of shame, culminating in a diabetes shame-bind that emerges any time that a patient is criticised (Archer, 2014).

Archer (2014) critiques the negative evaluations made by healthcare professionals, asserting that they often commend individuals with ‘good’ HbA1c levels for effectively managing their diabetes. Those well-intentioned, paternalistic remarks may reflect the professional's satisfaction in seeing the person closely adhere to their concept of an ‘ideal diabetic.’ Patients who experience frequent hypoglycaemia often disclose a fear of not meeting the standards of an ‘ideal patient,’ which they mitigate through continuous glucose monitoring. Perfectionism, in this case, is described as a defence mechanism against the potential shame of failing to be the ‘ideal patient’ (p.103). The dynamics highlighted by Archer (2014) speak to the quest for perfectionism has the paradoxical effect of eliciting shame in patients. Of note, public health messaging around diabetes, specifically concerning the linkages between diabetes and obesity has influenced the formation of stigma around the disease, particularly for T2DM patients who are classified as obese (Brunton, 2022). In this context, *‘all of society’s biases about obesity, its origins, and its consequences come into play’* (Brunton, 2022, p.9), and patients are stereotyped as lazy, gluttonous, lacking a sense of responsibility and also lacking self-control and regulation (Brunton, 2022;

McNaughton, 2013). These stereotypes culminate in stigmatisation which is perceived by PwD not only externally, but also internally so that they develop negative perceptions of themselves.

Indeed, the role of language and communication in relation to diabetes in public health messaging has received increasing attention. Responses to a World Health Organisation (WHO) informal consultation (Hunt et al., 2022) for people with lived experience of diabetes highlighted the ways in which stigmatising language may inadvertently perpetuate feelings of shame including the positioning of people living with diabetes as ‘patients’ and the prioritising of messages around prevention anchored in changes in behaviour may impact on health-seeking and falsely promote the message that all instances of T2DM are preventable through modifiable risk factors. To this end, a position statement from Diabetes Australia in (Speight et al., 2021) led to the ‘Language Matters’ publication series with the publication of a position statement for England in 2018 (Cooper et al., 2018) providing practical examples of language used in public health communications that would stimulate positive discourses around the experiences of those living with diabetes and mitigating problematic or ill-defined terminology encouraging, instead, the use of empowering strength-based language with a view to mitigating against stigma and resultant shame responses in those living with diabetes (Cooper et al., 2018).

1.3. The Epidemic of Diabetes and Pandemic of COVID-19

During the initial stages of the COVID-19 outbreak, it was observed that approximately one-third of the deaths associated with the virus involved individuals diagnosed with T2DM (Holman et al., 2020). Consequently, the UK government categorised those with diabetes (without differentiation of T1DM vs T2DM) as being in a ‘high risk group’ throughout the pandemic. However, this classification may have contributed to increased levels of anxiety regarding the management of T2DM, as well as adherence to official guidelines concerning social distancing and hygienic practices.

1.3.1. Diabetes Co-morbidity and COVID-19

The available evidence following the global outbreak of the COVID-19 pandemic suggests that individuals that have pre-existing comorbidities have a higher risk of dying from the virus than those who do not (Callender et al., 2020). Several studies have indicated that diabetes is a prevalent comorbidity that is linked to the severity of the virus (Bornstein et al., 2020; Cuschieri & Grech, 2020). Thus, the pandemic has been understood as being of major concern for the diabetes community (Beran, Lazo-Porras, et al., 2021). Estimates, at the time of writing, suggest that between 20 and 50% of COVID-19 patients have diabetes (Bornstein et al., 2020). This figure is, however, dependent on the geographic region. In a case series conducted in the USA that investigated 5,700 patients diagnosed with COVID-19, it was found that 33.8% of patients had diabetes making it the third most common comorbidity (Richardson et al., 2020). In a meta-analysis conducted by Kumar et al. (2020), it was found that the prevalence of diabetes in patients diagnosed with COVID-19 was 19.8%. The meta-analysis evaluated 33 studies published in China, France and the USA.

1.3.2. Risk in Diabetes Population during COVID-19

COVID-19 can cause serious complications in individuals diagnosed with diabetes (Cuschieri & Grech, 2020). Increased viral load to efficient virus entry is one pathway through which diabetes increases the risk of infection (Erener, 2020). As such, patients diagnosed with diabetes have a higher risk for worsened COVID-19 complications such as coagulopathy, vasculopathy and psychological distress (Cuschieri & Grech, 2020; Fogarty et al., 2020; Labò et al., 2020). As compared to individuals without comorbidities, PwD infected with COVID-19 experience a range of risks including higher mortality rates, higher admission rates to hospitals and higher incidences of pneumonia (Peric & Stulnig, 2020; Sathish et al., 2021). Patients with diabetes have compromised immune systems and humoral immunity, especially where their glycaemic status is uncontrolled (Cuschieri & Grech, 2020). Consequently, they have a weakened defence against infections including COVID-19.

The risk of pneumonia is also higher in PwD infected with COVID-19. Huang, Lim & Pranata (2020) conducted a systematic review and meta-analysis to evaluate the linkages between diabetes and poor outcomes in patients with COVID-19 related pneumonia. The study found that the risk of pneumonia is especially higher for PwD infected with COVID-19 that have uncontrolled glycaemic status.

Complications including ischemic heart disease and diabetic kidney disease can introduce additional complications for PwD by making them physically frailer further enhancing the severity of the virus and presenting the risk of heart or kidney failure (Erener, 2020). Richardson and colleagues (2020), in a US study, found that individuals diagnosed with diabetes have a higher risk of requiring mechanical ventilation. The study was, however, restricted to this population and the lack of data concerning patients who remained hospitalised at the final study date may have introduced biases into the findings, including the rate of patients who were placed on a mechanical ventilator and were age 65 years and above. The linkages between T2DM and the onset of ventilator-associated pneumonia when such patients are placed on machinal ventilators are also high (Cuschieri & Grech, 2020).

Obesity is a prevalent co-morbidity in individuals diagnosed with T2DM, and its associated adiposity influences both the innate and adaptive immune system. This is largely due to the induction of chronic systemic inflammation (Cuschieri & Grech, 2020). Meanwhile, COVID-19 infection is known to trigger inflammation and stimulate the release of cytokines, thereby raising the risk of potentially deadly cytokine storms (Codo et al., 2020). As diabetes itself is characterised by a pro-inflammatory state, individuals diagnosed with this condition are inherently more susceptible to intense inflammatory responses to the virus (Lontchi-Yimagou et al., 2013). Furthermore, the insulin resistance often seen in diabetes patients can be exacerbated by the increased circulation of cytokines (Tzeravini et al., 2022).

1.3.3. Diabetes and Management in COVID-19

From a public health perspective, existing guidance concerning the prevention of COVID-19 has important implications for at risk populations, including PwD (Beran, Lazo-Porras, et al., 2021). These implications are tied to the social isolation and distancing protocols upon which COVID-19 management is based. These social isolation and social distancing directives are contradictory to the exigencies of comprehensive diabetes care. As has been noted elsewhere in this chapter, diabetes requires regular healthcare provider communication and support to promote patient education and self-care (including prescription management), manage complications, reduce levels of diabetes distress and support the mental health of PwD more generally.

Romero-Blanco and colleagues (2020) suggest that social isolation may increase the risk of diets considered, by the researchers, to be unhealthy and an increase in sedentary lifestyles which are not conducive to managing diabetes successfully. Additionally, self-monitoring of blood glucose levels may be reduced as a result of social isolation (Singhai et al., 2020). Two cross-sectional studies reported conflicting results regarding the impact of the COVID-19 pandemic on the lifestyle behaviours of individuals with T2DM: Grabia and colleagues (2020) documented enhancements in healthy dietary habits during the early stages of the pandemic, while Ruiz-Roso and colleagues (2020) identified an escalation in snacking tendencies and elevated levels of physical inactivity among the T2DM population. A qualitative inquiry revealed heterogeneous self-reported outcomes among people with T2DM, encompassing both detrimental and health-promoting dietary and exercise practices (Grabowski et al., 2021). Whilst these three studies were conducted and published in Denmark, Spain and Poland, self-management practices of individuals with T2DM during the COVID-19 pandemic in the UK remain, at the time of writing, unexplored.

As described earlier in the chapter, before the pandemic, people with T2DM experienced higher rates of low mood and anxiety in comparison to the general population. These indications have been linked to diminished diabetes self-care, poor maintenance of blood sugar levels, heightened risk of diabetes-related complications and fear of mortality (Grabowski et al., 2020). In a comprehensive European survey involving 1,829 diabetes nurses, respondents noted a deterioration in patients' self-care practices, exacerbated glycaemic control and heightened psychological challenges including depression, distress and anxiety throughout the pandemic (Forde et al., 2021). Furthermore social confinement presents the risk of exacerbating existing mental-health related concerns as a consequence of a loss of social resource and existing psychosocial community based support (Beran et al., 2021). As such, Beran and colleagues (2021) have advocated for support to be provided to both physical and mental healthcare services alongside the pandemic response to ensure that PwD have access to an enhanced level of care; the value of such an approach is that it can assist in avoiding health consequences that are more severe than the COVID-19 infection. However, COVID-19 related lockdowns have led to delayed help-seeking and, where these lockdowns have been lifted, the fear of contracting the virus amongst some patients has potentially undermined their help-seeking (Singhai et al., 2020).

1.3.4. Help Seeking in the UK in COVID-19

The UK has experienced a significant transformation in healthcare service provision since the onset of the initial national lockdown, characterised by a decline in direct patient contact and a rise in remote consultations (Greenhalgh et al., 2021). A conspicuous reduction in individuals utilising the NHS was observed during the initial lockdown, with a 10% decrease in GP attendance and a 49% reduction in A&E admissions in March 2020 compared to March 2019 (Moynihan et al., 2021). This led to concerns about potential harm due to deferred help-seeking, prompting the implementation of the "Open for Business" campaign by the Office of Health Improvement and Disparities (Public Health England, 2020).

A systematic review from 20 countries revealed a median decrease in routine healthcare appointments by 41%, admissions by 28% and diagnostic and therapeutic procedures by 39% (Moynihan et al., 2021). Furthermore vaccinations, health screenings and elective surgical procedures have all been impacted raising concerns in relation to potential long-term negative health consequences (Kursumovic et al., 2021). Collectively, the literature indicates that fewer individuals sought assistance for a wide range of health concerns, from severe and life-limiting to routine and preventive, possibly resulting in detrimental health outcomes. Regarding help-seeking behaviour pertaining to non-COVID-19 matters, the GP Patient Survey conducted in the early months of 2021 identified that nearly half of patients who required an appointment with their GP refrained from making one (*Statistics » GP Patient Survey 2021*, n.d.). However, these surveys did not offer an in-depth understanding of the factors influencing individuals' decisions. To date, only a handful of qualitative studies have examined help-seeking behaviours during the COVID-19 pandemic, focusing exclusively on individuals living with specific health needs, such as sudden onset of chest pain (Ferry et al., 2021) and eczema (Steele et al., 2021).

Help-seeking decisions are influenced by various factors, including social and cultural contexts (Scott et al., 2013). Notably, within the pandemic context, self-regulation involves the collaboration and expertise of numerous individuals, including family, friends and neighbours, in addition to healthcare professionals (Prior, Evans, & Prout, 2011). Those with physical health needs may actively seek advice from friends or family members or symptoms and physical changes noted by others may be reflected back to the PwD (Baig et al., 2015; Fisher et al., 1998; Hempler et al., 2016).

In the T2DM population in the UK, HbA1c tests, a vital proxy marker for guiding clinical decisions to regulate glycaemic levels, declined by up to 77% between March and December 2020 (Carr et al., 2022). This reduction in monitoring of these levels highlights the significance of effective diabetes self-care in mitigating the risk of COVID-19 infection and its consequences. To enhance services for individuals with T2DM during and following the pandemic, it is essential to understand their perspectives on the impact of the COVID-19 lockdown on social isolation, diminished access to routine diabetes care, and the implications for understanding help-seeking behaviours and devising targeted interventions to improve health outcomes.

1.3.5. Theoretical Models of help-seeking behaviour

Theoretical models of help-seeking behaviour in healthcare settings offer a framework for understanding the intricate process individuals navigate when seeking medical help and advice. These models aim to illuminate the factors that influence a person's decision to seek healthcare, such as the recognition of symptoms, the evaluation of healthcare providers and resources and the perception of self-efficacy in managing one's health. A helpful framework to support understanding around and promote health related behaviours, the COM-B model (Michie, 2014) strives to integrate various biopsychosocial aspects related to self-help and help-seeking. Furthermore, these frameworks have been employed in interventions aimed at both individuals with diabetes and healthcare professionals to create culturally sensitive self-management support for people with T2DM in the UK, particularly within African and Caribbean communities (Moore et al., 2019). They have also been used to enhance general practitioners' prescribing and medication practices (Murphy et al., 2017). When applied to help-seeking, the central premise of the model (see Appendix A) is that the behaviour will occur when both capability (psychological and physical) and opportunity (physical and social) are present, and that these factors, along with motivation (reflective and automatic), are connected through reciprocal feedback loops. In the context of the COVID-19 pandemic, the COM-B model offers several advantages over alternative models and theories including, but not limited to, the Health Belief Model (Rosenstock, 2000), The Theory of Planned Behaviour (Ajzen, 1991) The Common Sense Model (Leventhal et al., 2016) and the aforementioned Self-Determination Model (Deci & Ryan, 2012). Firstly, where these models or theories may not cover the full range of possible influences so may exclude potentially important variables, the COM-B model provides a context sensitive and comprehensive framework that addresses a range of interacting and intersecting factors that accommodates unique pandemic characteristics including mandated lockdowns, social distancing measures and fear of contracting the virus (Gibson Miller et al., 2020). Furthermore, its dynamic and flexible structure allows integration with other models including the Behaviour Change Wheel and the Theoretical Domains Framework to inform intervention design and implementation at the action stage. However, the COM-B framework has faced criticism for being overly systematic and simplistic (Ogden, 2016), with some questioning whether the model can adequately address all aspects of a behavioural issue (Peters & Kok, 2016). Additionally, the COM-B model has been critiqued on philosophical grounds for potentially detracting from the concepts of empowerment and self-determination. Thus, in the context of T2DM, individuals may be expected to change their behaviours primarily in accordance with the perspectives of healthcare professionals or intervention developers (McSharry et al., 2020).

Understanding the reasons behind people's decisions to seek help for non-COVID-19 related issues during the pandemic requires acknowledging the complex interplay of underlying mechanisms and contextual factors that shape these decisions. At the time of writing, there is limited understanding of the driving forces behind help-seeking behaviours for non-COVID-19 issues amidst the rapid and ongoing changes in healthcare access and capacity challenges.

1.4. Scoping Review

The use of a scoping review methodology enables researchers to determine the extent to which there is coverage of a given topic in the literature and additionally helps to identify the approaches taken towards that topic (Munn et al., 2018). This approach is, therefore, suitable for exploring the experiences of PwD in the context of public health messaging and help-seeking behaviour during the COVID-19 pandemic, as examined up until July 2022. The approach outlined in the work of Booth, Sutton and Papaioannou (2016) was utilised to structure this review. The first step of this process was to define *who* this review would focus on; this would consist of exploring the experiences of PwD. The second step was to establish *what* to focus on (Booth et al., 2016) and for this review that would be lived experiences of the above population during the COVID-19 pandemic. With regard to *how* the study will impact on this population (Booth et al., 2016), the examination will focus on understanding help-seeking behaviours and responses to public health messaging.

1.4.1. Search strategy

As a means of increasing both the sensitivity and specificity of the search itself, multiple electronic databases were utilised, in line with the recommendations of MacLure, Paudyal and Stewart (2016). Keywords were developed on the basis of the above factors from Booth and colleagues' (2016) approach, and in order to further boost sensitivity and specificity, were combined with Boolean operators and truncation devices (Xiao & Watson, 2019). These were combined into a cyclical search syntax (Peters et al., 2015) which can be found in Appendix B.

The selection process consisted of a three-stage strategy as recommended by Khan and colleagues (2003).The first step of this involved appraising the titles of all returned studies and excluding any papers which clearly did not relate to this review. This was followed by the abstracts of remaining papers being examined within the context of the established eligibility criteria, with a further edit taking place at the end of this. The final stage was to read the full text versions of each remaining paper and select those that best fit the aims of this current review (Khan et al., 2003). A PRISMA concordant flow chart (Appendix C) details the outcomes of the above processes.

1.4.2. Overview of selected papers

A total of three studies were identified as addressing the experiences of people with diabetes in relation to help seeking during the COVID-19 pandemic with an absence of literature speaking substantively to public health and government messaging. Because of the limited number of studies found, each study will be individually summarised and assessed before presenting a consolidated overview of the main gaps. Although a scoping review does not necessitate a formal evaluation tool as a systematic review does, Yardley's (2000) principles for assessing quality in qualitative research were considered while reviewing the studies to maintain consistency (refer to Appendix D).

1.4.3. Joenson and colleagues (2020)

The aim of this quantitative study, from Denmark, was to determine the psychosocial health of people with diabetes in Denmark in response to public health messaging during the initial phase of the COVID-19 pandemic in the country. The study conducted a cross-sectional survey which was distributed online to 2,430 adults split into two user panels. These user panels comprised individuals with diabetes (including T1DM, T2DM and gestational diabetes) who volunteered to share their life experiences with regard to living with diabetes via the use of a questionnaire.

The study found that respondents had COVID-19-specific worries which were related to their diabetes. Over half of the research sample (56%) reported that they were worried about contracting the virus and having ‘at risk’ status because of their diabetes. Approximately one-third of the research sample was characterised as ‘at risk’ due to their diabetes and not being able to manage the disease if infected with the virus. The logistic regressions indicated that females, and those with diabetes complications, were more likely to experience anxiety. Anxiety was also linked with diabetes distress, isolation and loneliness. Some respondents showed signs of changed diabetes behaviours, which was also linked with being more worried about the virus and its relationship to diabetes.

The research revealed a connection between the anxiety levels of individuals and the public health announcements issued by the Danish government. People with Diabetes (PwD) were made aware of their high-risk status and the crucial need to adhere to health guidelines due to the increased severity of potential symptoms if they contracted the virus. During the onset of the pandemic, the Danish health authorities disseminated mixed messages, initially suggesting that only poorly managed diabetes increased the risk, only to later declare that all people with diabetes were at high risk. This inconsistency in government communication heightened anxiety among people with diabetes, not just due to the fear of virus transmission, but also from the stigma associated with being identified as a high-risk group.

Distinctions were not, however, made between diabetes subtypes, and for the most part, their experiences were amalgamated unless there was an outlier. Further, the convenience sample of respondents that was used was not generally representative of the average PwD because they had a very low prevalence of diabetes complications when compared to the general population. Notably, over half of the research sample had a comorbid condition; thus, while the risks associated with diabetes were found to serve as a source of anxiety for respondents, other underlying health issues might have been at play. Further, all measures that were featured in the study are self-reported, introducing possible biases and uncertainties about the prevalence of diabetes complications, glycaemic levels and comorbidity. Finally, the validation of the questionnaire was undermined due to the exigencies of the pandemic. The questionnaires were administered during the early phase of the pandemic when concerns about COVID-19 were emerging, which could have skewed the results concerning respondents' anxiety levels.

1.4.4. Distaso and colleagues (2022)

This online survey sought to measure the impact of social distancing measures on the mental health of diabetes patients and their self-management in the UK. Distaso and colleagues (2022) distributed surveys to individuals attending diabetes clinics in three London hospitals. The research participants also completed the COVID-19 Anxiety Syndrome Scale (C-19 ASS), which measures avoidant maladaptive coping behaviour and perseveration well as measures of co-existent anxiety and depressive symptoms, in addition to completing the Diabetes Self-Management Questionnaire (DSMQ). The C-19 ASS controlled for gender, age and social deprivation. The study found that lockdown measures profoundly impacted respondents' mental health, with C-19 ASS scores suggesting high levels of COVID-19 anxiety for over half of the respondents. Further, over a quarter of the research participants recorded PHQ-9 scores which were indicative of clinically relevant depressive symptoms. Higher C-19 ASS avoidance subscores were correlated with better diabetes self-care in the cohort at the height of lockdown measures. Participants who scored high on the C-19 ASS avoidance subscale sought more help from their healthcare provider as compared to cohorts who scored lower on the scale. Further, improved self-care was linked with staying at home, as physical activity scores were low for participants who recorded high C-19 ASS scores. There is the suggestion, therefore, that staying at home enabled them to maintain their schedules and routines with regard to eating and other aspects of self-care (Distaso et al., 2022).

This study provided insight into the impact of social distancing measures on diabetes patients' mental health and their help-seeking behaviours; however, it was concomitant with certain limitations. Firstly, the study incorporated those individuals diagnosed with either T1DM or T2DM diabetes and, therefore, did not consider the differences in self-care, management and lived experiences across these very different conditions. The results were not disaggregated according to the diabetes subtype, and thus, the nuances of help-seeking based on the unique challenges of each of these conditions cannot be determined. Most cases of T2DM are self-managed through diet, exercise and medication, and it is possible that improvements in self-management were limited to cohorts with this subtype. The study, however, did not differentiate its findings based on subtypes of the disease. Further, the research sample was not demographically representative of the diabetes patient population in the UK, as the sample was disproportionately White. Levels of HbA1c in the study cohort were also lower than the London average for people diagnosed with diabetes, which undermines the external validity of the study.

1.4.5. Sauchelli and colleagues (2021)

This mixed-methods study measured the mental health impacts of social distancing policies on people living with diabetes in the UK (n=773). Sauchelli et al. (2021) distributed an anonymous online survey during the lockdown period and after the initial easing period. The survey encapsulated questions regarding diabetes self-management and resources used to acquire information, support and advice. Through the use of open-ended questions, the study captured the subjective experiences of respondents. The study included adults with both diabetes subtypes, with 69.2% of the research sample represented by T1DM, while 28.5% represented T2DM. The study found that there was significant variability in how the pandemic impacted the confidence levels of respondents with regard to their self-management of the disease. Further, there was a notable decline in their confidence in their ability to care for their mental well-being, with 37% of respondents reporting this challenge. Crucially, 41.2% of the respondents lived alone and reported that they did not receive any external support. Against this backdrop, respondents reported poor access to advice and support and wanted improved communication and tailored advice from the healthcare providers. Government and media messaging was found to be problematic as a result of inconsistent information, which made it difficult to access advice about seeking help and accessing resources. Personal networks, however, constituted an important compensatory source of information about self-care. Sauchelli et al. (2021) found that the pandemic was concomitant with declines in respondents' mental health and motivation to seek help or continue self-management.

Poor mental health was linked with reduced support and advice and the cancellation of hospital appointments. Since the study was predominantly distributed online, the responses are limited to respondents who have a degree of digital literacy; thus, the survey does not accurately capture the experiences of diabetes patients who do not have access to technology, including older adults. This demographic has unique challenges that may shape their experiences of help-seeking, however, these experiences were not captured. Racially minoritised groups were also underrepresented in the study, despite the higher prevalence of diabetes in this demographic group in addition to the unique challenges experienced in accessing healthcare due to their intersectional experiences of discrimination, sexism, poverty and other contextual factors which may influence their help-seeking. Further, data collected from the study did not take into account the changes that occurred in government messaging between April and August 2020. Changes in government messaging could have influenced perceived support and access to resources, which could potentially influence help-seeking behaviours. Further, the study did not differentiate its findings according to the diabetes subtypes despite patients’ unique experiences of the diseases. Consequently, the specific experiences of people with T2DM and T1DM could not be adequately explored.

1.5. Gaps in the literature

The review of the literature above indicates the significant lack of current research pertaining to the impacts of - and responses to - public and government messaging with diabetes and COVID-19. There is also a notable gap with regard to studies that explicitly differentiate how people with T2DM and T1DM describe help-seeking in relation to COVID-19. This review identified three studies which have been conducted since 2020 and one of these did not use a UK sample. Of the limited research that exists, no studies have examined the help-seeking behaviours of specific subgroups of diabetes and the impacts of public messaging about diabetes and the virus. All but one of the studies recruited their research sample via online platforms meaning that details and nuance pertaining to the experiences and barriers faced by older adults with T2DM may be lost since they are less likely to be digitally present or digitally literate. In one study, questionnaires were administered during the early phase of the pandemic when concerns about COVID-19 were emerging, which could have skewed the results concerning respondents' anxiety levels (Joensen et al., 2022) and the evolving picture of the pandemic may have been lost. Despite the growing body of research on COVID-19's impact on individuals with chronic illnesses, most studies have relied on questionnaire-based or online methods employing a cross-sectional design. While these studies provide valuable insights, they fail to delve deeper into the lived experiences of those suffering from particular illnesses. Furthermore, the use of predetermined questions may inhibit participants from expressing their most significant concerns, potentially skewing the findings to align more closely with the researchers' interests rather than the participants.

1.6. Research Rationale

The gaps in the literature identified above point to the need for further research to understand the experiences of people with T1DM and T2DM autonomously in light of the variables in both management and the existing literature on the mental health outcomes of each group. Further research is additionally required to gain a nuanced understanding of the role of public and government messaging related to the pandemic and diabetes in shaping patients' mental health responses. These mental health responses may have long-term repercussions, which must be understood to design appropriate and targeted interventions. While diabetes and mental health are widely acknowledged as important public health concerns, the literature base on their linkages during the pandemic remains small as there has been a tendency to focus on physical health during the pandemic despite the widely researched experiences of stigmatisation and resultant shame experienced, most notably by people living with T2DM.

Against this backdrop, the present study seeks to expand the existing knowledge base concerning the experiences of PwD in seeking help and the potential impact on mental health outcomes in response to public and government messaging linked to the pandemic. To the researcher’s knowledge, there are no studies to date which are exploring this area in the UK. As previously noted, existing studies amalgamate the experiences of people with T1DM and T2DM; thus, their experiences cannot be differentiated. As such, and in light of the distinct underlying causes and management strategies of each subtype, this research will focus on the experiences of people with T2DM. This is in light of its higher prevalence, stronger association with obesity and other comorbidities which are known risk factors for severe COVID-19 outcomes thus necessitating targeted interventions to protect this population. Furthermore, a more detailed understanding of the unique challenges of this group will help to facilitate the development of targeted interventions and recommendations to improve health outcomes.

The underlying motivations or limitations around individuals' decisions to seek assistance for non-COVID-19 related concerns during the pandemic remain insufficiently understood. In light of the swift and continuous alterations to healthcare accessibility and the challenges posed by capacity constraints, help-seeking for non-COVID-19 issues may leave a lasting impact that requires a more profound understanding to inform public health communication strategies effectively.

1.7. Research Questions

This research aims to explore the experiences of individuals with T2DM living through the COVID-19 Pandemic by addressing the following questions :

- What are impacts of – and responses to – public and government messaging around T2DM and COVID-19?

- How do people with T2DM describe help-seeking in the context of COVID-19?

2. METHOD

2.1. Overview

This chapter begins by considering epistemological and ontological aspects relevant to the study. Thereafter, the chapter will go on to outline the design, including procedure and participants before concluding with personal reflexivity to examine the relationship between the research and the researcher.

2.2. Epistemological and Ontological Considerations

This study will adopt a critical realist perspective, which can be understood through an examination of ontological and epistemological assumptions. Epistemology concerns the nature and discovery of knowledge and is guided by the scope, limits and processes by which knowledge can be acquired (Willig, 2008). Ontology, on the other hand, pertains to assumptions about the nature of existence and the understanding of reality (Crotty, 1998).

Realism emphasises the pursuit of reliable knowledge about a world that exists independently of an observer's awareness. This approach to understanding reality can be seen on a continuum, ranging from naive to critical. Naive realism is associated with positivism, where truth is believed to be discoverable and observable through processes such as quantitative experimental designs (Alderson, 2021). It assumes that knowledge can be considered a fact and directly reflects a universal reality. An example of positivism is evident in the categorisation of psychological distress which leads to the emergence of mental ‘disorders’ or diagnoses. This approach views psychological distress as an external natural disease that exists independently of awareness (Wakefield, 2007).

By contrast, social constructionism states that multiple realities exist and that knowledge of the world is always historically, socially and culturally situated with no ultimate truth that transcends culture and context (Burr, 2015). An example of this is the construct of homosexuality which had previously been pathologised as a ‘mental illness’ but has now been understood through the reformulation of social and cultural constructs and understandings (Drescher, 2015). Critical realism, originating from Bhaskar's theory (2008) sits between these two positions and posits that there is an independent reality, yet our knowledge of it is constructed through social, cultural and historical contexts, rendering it partially socially constructed. According to Edgley and colleagues (2014), critical realism goes beyond merely identifying discourses and instead seeks to comprehend the underlying factors that shape our understanding of the world and how things come to be.

Ontologically, critical realism assumes a realist position: that material and social structures hold an objective reality that exist and can be observed and measured independently of one’s beliefs and awareness of it (Willig, 2019). As such, the researcher acknowledges the existence of physical illness as phenomena that is only able to be explored through an individual’s own context and, as such, recognises that their participants’ perspectives on diabetes and COVID-19 will vary. Furthermore, the assumption is made that the experiences of participants are ‘real’ and can be explored and that diabetes is a disease that has a ‘real’ impact on the mind and body. Despite this, the researcher acknowledges that participants themselves exist within independent personal, cultural, social and familial contexts which will have influenced their experiences of their existing disease and, indeed, the evolving pandemic. As such, the study does not aim to uncover objective or universal truths, but instead seeks to cautiously make sense of the findings and contextualise them in light of this limitation.

In summary, within the scope of research conducted on the intricate socio-epidemiological interplay between COVID-19 and diabetes, a critical realist approach fosters an understanding of the open system of the social world. In this framework, the relationship between mechanisms and events transcends a simplistic cause-and-effect model, and instead emphasises the multifaceted interactions among context, structures and agents. This perspective helps to facilitate richer interpretations beyond the surface of observable symptoms in order to comprehend the experiences of underlying, less visible processes. By employing a critical realist lens, we can better grasp how the social determinants of health, healthcare access and systemic factors converge to influence the experiences of individuals living with diabetes during the COVID-19 pandemic, as well as the broader implications for healthcare systems and policy (Correia & Willis, 2022).

2.3. Design

With the research questions and epistemological stance in mind, a qualitative methodology was adopted. Individual semi structured interviews were used to support the design of the researcher's exploratory stance in recognition that, at the time of writing, individual perspectives in this area have received sparse attention. This approach would allow for the opportunity to gain 'unexpected insights' (Wilkinson, 2004) during conversations in order to provide richer understanding of individuals experience of COVID-19 whilst living with T2DM. Whilst the use of focus groups was initially considered as a suitable alternative, consideration of the potential for group dynamics to inhibit open discussion may have resulted in the marginalisation of certain perspectives thus limiting the richness of the data collected. Furthermore, an analysis of data from open and closed questions via a survey was considered due to the more substantive sample size however, due to the nature of the research and its live context, there was concern that data may not have been as rich or nuanced and may limit the analysis that may be performed. In addition, the variation in terms of the amount of data collected may lead to a loss of depth resulting in a potential lack of understanding by the researcher and, as such, only a superficial interpretation being possible.

2.4. Ethical Considerations

The study was registered with the University of East London. Ethical approval was granted (see Appendices D-G) following minor amendments requested by the UEL Ethics Committee. As ethics is central to the research, so the implementation and design complied with the BPS Code of Human Research ethics (2021). As participants were not recruited through the NHS, further ethical approval was not required. By way of protecting participants from adverse effects, the researcher obtained informed consent, sustained confidentiality and worked to manage levels of distress during interviews.

2.4.1. Informed Consent

Prior to interview, informed consent was obtained for the study by sharing with all participants a Participant Information Sheet (Appendix H) describing the aims of the study, what participation would involve, information about confidentiality, withdrawing without consequence and the potential benefits and risks of taking part. Participants were advised to retain a copy as contact details for both the researcher and their supervisor were provided. Participants were invited to make contact should they have any concerns or questions and were informed that they could withdraw from the research process in the lead up to, during, and up to three weeks after the interview. A participant Consent Form consisting of several statements relating to participants' understanding of their rights was completed in advance of the interview and a digital copy sent for their records (Appendix I).

2.4.2. Potential Distress

The researcher considered the possible discomfort that participants might encounter when discussing the experiences of living with diabetes (Browne et al., 2013b). To mitigate this, the researcher devoted time to establishing a connection with the participants aiming to ensure that they felt at ease during the conversation. The interview format was considered, beginning with broader questions about their diabetes diagnosis before exploring more recent events amid the pandemic. This gradual approach was considered with the aim of minimising potential harm, enabling participants to become acclimated to the process and feel more at ease when sharing their experiences. The researcher remained vigilant for indications of distress and maintained a pace that suited the interviewee. Additionally, participants were reminded of their option to withdraw and that they were not obligated to respond to all questions. As a Trainee Clinical Psychologist, the researcher was experienced in handling emotional material and felt assured in identifying and addressing distress.

2.4.3. Confidentiality

Within both the Participant Information Sheet and during the initial conversation at the beginning of interviews, participants were informed that the information would be anonymised and that their details would be held confidentially throughout data collection, analysis and storage. All recordings from interviews would be anonymised before being deleted post-transcription. Transcripts would be held on a secure cloud only accessible to the research team. Participants were advised that all data would be destroyed after three years in accordance with the Caldicot Principles (National Data Guardian, 2020) and the Data Protection Act (2018). Please see Appendix J for further detail of the Data Management Plan.

2.4.4. Debrief

Following interviews, participants were provided with the opportunity to ask questions or discuss challenging feelings or concerns raised by the interview. Thereafter, a Participant Debrief Sheet (Appendix K) was shared including a summary of the study, information about confidentiality and a list of relevant organisations and resources was provided.

2.5. Participants

2.5.1. Recruitment Strategy

Convenience and snowball sampling was employed to recruit participants. With an eye on reaching a point at which conceptual generalisations could be drawn from a potentially heterogenous range of experiences during the pandemic (Pope & Mays, 2006), a broad range of participants was sought with minimal demographic exclusions. A range of online forums (including Diabetes UK, The Royal College of Nursing Diabetes Forum and The Men’s Health Forum) as well as social media platforms (e.g. Facebook and Twitter) were used to advertise the study. Furthermore, following correspondence with Diabetes UK, all regional support group facilitators were sent the recruitment poster in both digital and printed formats (Appendix L). Pertinently, organisations contacted were engaged and supportive in the aspirations of the research and hoped to gain feedback on findings for further consideration around third sector support and resource for those living with diabetes.

2.5.2. Inclusion Criteria

To be eligible to participate, individuals had to meet the following criteria:

- Diagnosed with T2DM before 1st March 2020
- Tested positive for COVID-19 via either PCR or Lateral Flow test since 1st March 2020
- Aged 18+
- Living in the UK presently and since 1st March 2020
- Speak sufficient English to facilitate understanding of written materials and able to engage in conversation without an interpreter
- Able to access and use Microsoft Teams and/or a telephone

Notably, the decision to require a positive PCR test was designed to enable the exploration of how contracting COVID-19 might affect help-seeking behaviour among PwT2DM both before and after possible vaccination. This also allowed for investigation into how they may have experienced the onset of the virus given the simultaneous presence of both T2DM and COVID-19.

2.6. Procedure

2.6.1. Initial Contact

Prospective participants viewed the research advert (online or via posters) and made contact with the researcher via e-mail. The researcher then shared additional information regarding the study and invited potential participants to share any questions or reflections on the potential challenges or benefits of their participation and thus make an informed decision. The researcher then gained informed consent via the Consent Form (Appendix I) and preceded to arrange a convenient date and time for the interview following receipt of the completed consent form. Consent forms were reviewed prior to commencing data collection.

2.6.2. Remuneration

In return for their contribution of time, participants were offered a £10 Amazon voucher. The researcher emphasised that compensation was solely a gesture of appreciation for their attendance (see Appendix H).

2.6.3. Individual Online Interviews

Before commencing interviews, participants were invited to fill out a brief demographic information form (Appendix M). A semi-structured interview schedule was utilised to guide interviews (Appendix N) and facilitate the exploration of their experiences of living through the COVID-19 pandemic as a person with T2DM alongside their views and experience of receiving help and advice through formal and informal means. The interview schedule was collaboratively developed with the research supervisor in light of the research questions and the existing body of literature. Prepared cues were developed to support discussion in the event of a participant struggling to elaborate on their experiences. A pilot interview was performed to facilitate necessary refinements including the reordering and rewording of questions, as well as the addition of two questions following feedback from the pilot participant. Furthermore, it was considered a continually developing process based on feedback and reflection as the interview process took place.

Interviews lasted approximately 60 to 90 minutes. At the conclusion of each interview, the researcher offered a written and verbal debrief with the opportunity for participants to reflect on their experience of participating in the study before consent was revisited (Appendix K). All interviews were video and audio recorded on Microsoft Teams.

2.6.4. Transcription

The researcher carried out and transcribed interviews to enhance familiarity with the data and contemplate their role as the interviewer. An orthographical transcription style was employed, as suggested by Braun and Clark (2013). Guidelines proposed by Bannister et al. (2011) were utilised and served as a reference for transcription (Appendix N). Participants' names were replaced with numbers, identifying information was substituted within parenthesis, and punctuation was incorporated for improved readability. Pauses were deemed to possess limited analytic value (Bannister et al., 2011) and, as a result, only pauses exceeding three seconds were documented. Transcripts were subsequently scrutinised and read multiple times to ensure accuracy and anonymity (Gibbs, 2018).

2.7. Analytic Approach

2.7.1. Thematic Analysis Justification

Thematic Analysis (TA) was the chosen method of analysis due to its helpful relationship to under-researched phenomena and socio-cultural contexts, such as the inter-relationship between diabetes and COVID-19 within specific cultural or social contexts. TA offers theoretical flexibility and enables researchers to identify and interpret meaningful patterns and relationships, in line with this study's epistemological position, thus facilitating rich interpretation and sense-making (Braun & Clarke, 2006; Clarke & Braun, 2013).TA can also be used to explore socio-cultural factors that impact health behaviours and attitudes, as well as the impact of social determinants of health such as the experiences of individuals living with diabetes during the COVID-19 pandemic.

While Interpretative Phenomenological Analysis (IPA) is another approach that could be used to explore under-researched phenomena, particularly in the context of individual experiences and subjective interpretations of illness experiences (Smith et al., 2009), TA was considered more suitable for identifying key themes and patterns of experience across individuals. Furthermore, TA was considered more useful in answering the study's research questions as it allows the researcher to draw together patterns arising in participants ideas around seeking help and the ways in which messaging throughout the COVID-19 pandemic may have had some bearing on help seeking behaviours, with a focus on views across the group of participants rather than individual lived experience. TA also provided an opportunity for the researcher to reflect on their own position having lived through the COVID-19 pandemic.

2.7.2. A Hybrid Inductive/Deductive Approach

A hybrid approach of both deductive and inductive TA was used to generate codes, themes and interpretations, with an emphasis on taking an inductive approach in that themes and interpretations were guided by the data (Braun & Clarke, 2006). The researcher recognises that their own experiences, meaning making and reflections through their relationship to their own health and journey through the COVID-19 pandemic will lead to beliefs and assumptions that may influence their active construction of themes in the data. Furthermore, where TA has been criticised for a lack of recognition of the researcher's role in shaping interviews (Nowell et al., 2017) a research journal was used to record reflections on the researcher's role in both data collection and its analysis (Nowell et al., 2017). In employing an interview schedule, a top-down approach is somewhat enforced, therefore a partly deductive approach is unavoidable. To negate the impact of potential decontextualisation (Mishler, 1991), a 'contextualist method' was employed to enhance the ability of the research to attend to both manifest and latent level themes that examine the data within its broader context rather than interpreting it solely based on its surface level content. Furthermore, in collaboration with the research supervisor, an iterative and collaborative approach was used to develop themes that accurately represented the data and its context. In maintaining the critical realist approach, however, the researcher recognises interpretations as tentative and that alternative understandings were available in reading the data.

2.7.3. Stages of Analysis

Braun and Clarke's six-phase approach (2006) was used to help guide the analysis in order to maintain transparency and consistency throughout the process (Sandelowski, 2000).

1. **Familiarisation with the data**: Immersion in the data began with conducting interviews and transcription as this process of familiarisation is understood as an interpretive act (Lapadat & Lindsay, 1999). Further immersion ensued during a process of repeatedly and actively rereading transcripts checking both for accuracy but also potential ideas or themes arising, thus beginning the process of pattern identification.

2. **Generating Initial Codes**: Codes are considered the building blocks of analysis, the smallest unit of meaningful information, which is connected to a segment of language, image or text (Saldaña, 2013). The data set was systematically coded using NVivo 13 software, enabling the emergence of possible patterns and themes driven by both data and theory. Inclusive data coding was employed to preserve essential contextual content and data was

frequently coded multiple times to reveal potential patterns and meaning. Initial codes and transcript examples are available in Appendices O-Q.

3. **Searching for Themes**: Codes sharing common or unifying features were clustered into overarching themes and subthemes and visual maps of these themes were created capturing salient patterns in the data (Appendix R).

4. **Reviewing Themes**: Themes were reviewed alongside the original data to assess coherence and accuracy of the reflections along with the research supervisor themes and subthemes were reviewed and rearranged using visual thematic maps to capture valid themes in relation to the whole data set.

5. **Defining and Naming Themes**: The core essence of each theme was reflected upon with the research supervisor with a view to generating concise and informative thematic names that was selected to help structure the narrative of the research (Braun & Clarke, 2013).

6. **Producing The Report**: In the final composition of this report, a cohesive narrative of the data was assembled. Themes were examined using anonymised excerpts that encapsulated the core of each theme and subtheme. Careful consideration was given to the order to ensure the communication of a coherent narrative.

2.8. Reflexivity: The researcher’s position

Reflexivity is the process by which qualitative researchers critically examine their own position, biases and assumptions in relation to the research they are conducting (Berger, 2015). It involves recognising that the researcher's personal background, values and experiences can shape the research process and influence the interpretation of data (Willig, 2008).

According to Finlay (2002), reflexivity involves acknowledging that the researcher is an active and interactive part of the research process and recognising the potential impact that the research may have on the researcher, as well as on participants.

To reflect on the researcher's positionality and consider how their own identity, experiences and values may influence the research, a reflexive journal was maintained. This journal documented responses to the impact (emotional or otherwise) of living through the COVID-19 era, acknowledging that the research was conducted during the global pandemic which permeated all aspects of the clinical training. Furthermore, within a critical realist stance, reflexivity plays a crucial role, as it emphasises the recognition that research findings are not presented as universal or objective truths and the researcher's impact on the generation of codes and themes is inevitable.

To encourage the reader to contemplate the researcher's influence on the data, several elements of the researcher's identity and experience, which appear relevant to the development and analysis of this research, are presented below:

- **Power**: As a researcher, collaborating with research participants, there is an inherent power imbalance with the researcher occupying a potential position of authority in the fundamental design and implementation of the research with the potential for participants to perceive their position as passive and unable to challenge the researcher’s perspectives or interpretations.
- **Positionality**: Identification as a white middle-class male belonging to various minority groups potentially resulting in similar lived experiences as research participants. The researcher’s privilege in terms of his race and class is acknowledged and it is recognised that this may hold some bearing around a further power imbalance in relation to participants. Furthermore inherent aspects of whiteness may lead to problematic blind spots and impact on questions being considered during interviews.
- The researcher and participants may have had varying experiences of loss and severe illness in others during the COVID-19 pandemic, which could influence their experiences of seeking help and support for underlying health

conditions throughout the pandemic. The fluid boundary between being an 'insider' and an 'outsider' to these experiences (Sherif, 2001) was crucial to consider, especially in terms of navigating the shared experience of living through a pandemic and the researcher's inclination to relate to descriptions that resonated with their own experiences.

- **Employment:** Being an employee of the National Health Service (NHS), it is important to acknowledge the potential influence on participants' perspectives, given the positioning of NHS services. There may be an increased likelihood of social desirability during interviews, as the researcher might strive to be perceived positively by participants and distinguish themselves from any barriers or negative experiences of care encountered elsewhere within the system. This may lead to conversations that miss discussion and inquiry around practice or policy that was hostile or exclusionary.
- The researcher's personal and professional experiences observing unhelpful encounters within NHS services have contributed to their belief that the system can sometimes be obstructive and unhelpful. This perspective may cause the researcher to be overly sensitive to, and place emphasis on, narratives related to adversarial or uncooperative actions within the NHS system.
- **Education**: The critical stance of the training at the University of East London has enforced strong beliefs regarding attending to power within relationships and systems and needing to create space to understand marginalised voices and resisting narratives and systems that oppress certain groups.

The researcher sought to maintain a reflective position throughout the research and will address this process and his position during the discussion.

2.8.1. The Researcher's Relationship to the Field of Study

The genesis of this research was inevitably shaped by the researcher arriving at clinical training during the early stages of the COVID-19 pandemic. As the world grappled with the emerging and evolving nature of the virus, there was a discernible shift in the landscape of both healthcare delivery and the potent role of international research and academia. The second wave of the pandemic, during which initial research ideas were beginning to percolate, offered fresh insights into the disease progression and, indeed, the psychosocial impact of COVID-19 in new and potentially unexpected ways. Parallel to this, the researcher’s knowledge base was further augmented by the Royal Society of Medicine Webinar Series with one episode, in particular, shedding light on the relationship between government, public health messaging and the impact of these on the delivery of care in the UK. This debate spoke to the need for research that scrutinised the interface between public health crises, messaging thereof and chronic disease.

Opportunities for collaboration were plentiful, especially given the researcher’s position within a service led by a member of the Long-COVID research team at University College London. Specifically, the suggestion by the service lead to conduct Key Stakeholder Interviews introduced the researcher to a wealth of perspectives from clinicians and researchers within the field of 'underlying health conditions’ including cardiovascular disease, obesity and diabetes. This process led to the development of a compelling metaphor describing the intersection of the COVID-19 pandemic with what the media has described as the ‘epidemic of diabetes.’ It was in this metaphorical intersection that the focus on the relationship between diabetes and COVID-19 solidified.

The thread of collaboration persisted throughout the research process and is particularly visible in the formulation of the research questions. In light of the literature review, the research question was reformulated collaboratively with the research supervisor over a period of time. During this stage, potential assumptions, the role of language and inherent biases were acknowledged and addressed as the researcher and their supervisor strived to ensure these factors were mitigated in the development of the research questions.

3. ANALYSES

3.1. Overview

In this chapter, demographic information is presented to contextualise the sample alongside participant numbers to ensure anonymity. Reflexive thematic analysis was employed to explore the research questions and a thematic map is shared. The themes emerging from individual interviews are presented. Themes and subthemes are elucidated using extracts from the transcripts to support the narrative, which have been edited for readability.

3.2. Sample Characteristics

Thirteen participants participated in the study and all of them completed individual interviews without any dropouts or withdrawals of consent to use data.

Seven participants self-identified as female and six as male which is approximately proportionate to gender differences in the prevalence of T2DM in the UK (Diabetes UK, 2021). Five of the thirteen participants identified with belonging to a racialised community. The reductive nature of ethnic classification in healthcare is noted as each classification represents a diversity of dietary patterns, cultural understandings and access to healthcare relevant to the research. Duration between the time of receiving a T2DM diagnosis and the interview ranged from three months to eighteen years (M=4yrs 10mths, SD=5yrs 7mths). Of note, two participants had received a T2DM diagnosis within six months of the start of the pandemic. Participant demographics are presented in Table 1.

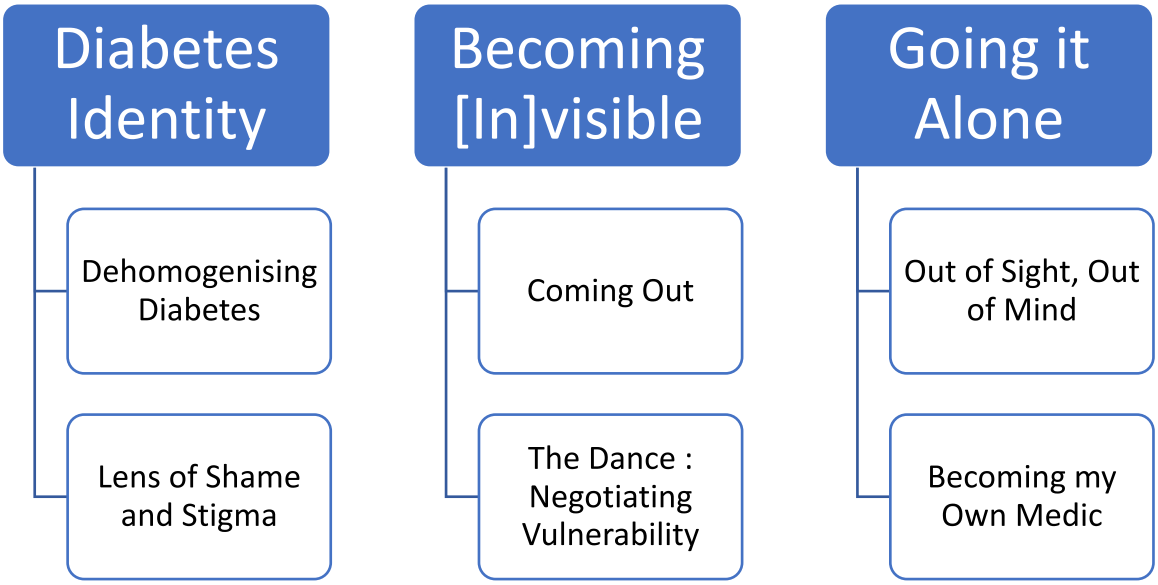
Table 1 : Participant Demographics

Participant Identifier	Age	Gender	Ethnicity	Time since Dx at interview
P1	26-40	F	White British	1-3 years
P2	41-55	M	Asian	1-3 years
P3	41-55	M	White British	1-3 years
P4	56-70	F	White British	4- 6 years
P5	56-70	F	Arab	9+ years
P6	41-55	F	White British	1-3 years
P7	56-70	M	White British	4-6 years
P8	26-40	F	Black British	9+ years
P9	26-40	F	White British	<1 year
P10	56-70	M	Asian British	< 1 year
P11	56-70	M	White British	1-3 years
P12	56-70	F	Black African	4-6 years
P13	71-85	M	White British	1-3 years

3.3. Thematic Map

In line with Braun and Clarke's (2013) six-stage approach to thematic analysis, multiple thematic maps were constructed and refined (Appendix Q) ultimately resulting in the final map (refer to Figure 1). The analysis was guided by the research questions, utilising a ‘top-down’ and ‘bottom-up’ approach.

Figure 1 : Thematic Map



3.4. Theme One : Diabetes Identity

This theme captures the various and wide-ranging experiences of PwT2DM including participants’ relationship to their diagnosis including the duration of illness, interaction with employment and positioning in the context of identities held. In the context of COVID-19, the re-evaluation of individuals' identities was examined, taking into account the time elapsed since their diagnosis and the extent of assistance they have received so far. Recognition that diabetes was not a uniform experience was expressed with acknowledgement of the diverse social, economic and cultural factors that shaped the experience of living through the pandemic with T2DM. Resultant experiences of stigma and shame were heavily experienced in light of contributions from government and public health messaging and contemporary discourses relating to T2DM through the lens of the COVID-19 pandemic.

3.4.1. Dehomogenising Diabetes

The experiences described, of the pandemic, were ones of diabetes being treated as a homogenous entity neglecting to hold the multiple and heterogenous experiences of the disease and its interaction with the COVID-19 pandemic despite *“everyone* *talking about diabetics as one huge group of people"* (Participant 5). Differences in both T1DM and T2DM were discussed in reference to *"needing to be more specific about what we needed to know and not shoving us all into one box of underlying health conditions"* (Participant 12). The impact of this was reported as "*diminishing*" (Participant 9) and leaving participants *"worn down by hearing some people who felt fine with [it] all when I was shitting myself. It really wasn't the same for everyone"* (Participant 1). Many participants described the impact of this as a barrier to accessing help and support from healthcare providers:

> *"Early on, I found it really hard to know where to turn for a straight answer. I ended up using the Diabetes UK forums because it was hard to know what was really…what really mattered to diabetics … you just saw everyone was dealing with it differently but we were being talked about … like you were all in the same boat and you weren't."* (Participant 2)

These differences were further experienced in relation to the variation in other factors including the existing relationship with healthcare providers, the duration of illness and efficacy of ongoing management of T2DM. Furthermore, participants described that a one-size-fits-all approach to disseminating information and providing support may not be sufficient given the diverse circumstances and experiences of individuals living with T2DM:

> *"I really picked up that it depended how well your diabetes was connected to your GP and how long you had it, how bad you had it or how stable it had been, so it had to be unique to each person how you got information."* (Participant 3)

The redefinition and evaluation of participants' diabetes was described in accounts speaking of *"becoming diabetic all over again"* (Participant 1) with diagnoses being brought into sharp focus after long periods of normalisation:

> *"…during the pandemic, I probably said the words 'diabetes' or 'diabetic' about 20 times a week maybe and maybe once a year before that"* (Participant 11)

> *"I'd not really thought about the diabetes for years as I wasn't on medication and just got an appointment every year for blood tests. And suddenly it's a big deal and my daughter is having a meltdown about it and I am expected to live my life a certain way because of diabetes."* (Participant 3)

This recalibration spoke of *"a double threat"* (Participant 8) with the realisation that the unknown aspects of the emerging virus was meeting with unknown aspects of diabetes control and management:

> *"You were scrambling around to see if your [blood sugar] levels were okay and if you needed to be on medication or should you be having other health checks when…bam….it was here and it was too late to do anything about it"* (Participant 10)

This double threat was described as contributing to a shift in how participants had positioned themselves in relation to their pre-existing health condition during the pandemic and conceptualisation of their 'illness' with *"a new understanding of what it meant to be diabetic"* (Participant 1) when framed within a dominant medical framework of understanding around COVID-19:

> *"COVID forced me, for the first time in 14 years, to actually need to understand what was happening to my body with diabetes rather than just getting good numbers on blood test results. And I was like, well, I might have taken better care if I'd known then what I know now."* (Participant 5)

This description speaks to the pandemic serving as a catalyst for the individual to go beyond focusing on achieving favourable blood test results and to gain a deeper comprehension of their body's response to diabetes rather than conceptualising themself as fitting a singular and predetermined measure of health. This newfound knowledge led to a realisation that they might have taken better care of their health had they possessed this understanding earlier. Indeed, whilst this focus on the underlying processes of diabetes was a unifying feature of most participant experiences, responses were varied:

> *“Inflammation was talked about and that I might get more unwell as a diabetic or COVID would connect with the diabetes in some way differently. But no one could say really how or why for sure, or if it was diabetes, or blood pressure or if it would be the same for everyone who was diabetic or not so I just carried on as they didn’t seem to know their arse from their elbow anyway.”* (Participant 7)

These descriptions of diabetes and identity may speak to the variance in the conceptualisation of diabetes around primarily biological factors with dominant diagnostic criteria that were ignited during the pandemic with a focus on symptomology and pathological characteristics of ‘illness.’ Descriptions of pre-COVID conceptualisation of diabetes spoke to the meaning making of the individual in the context of cultural scripts and attitudes towards diabetes being displaced by homogenised attitudes towards diabetes as a biomedical issue alone:

> *“My diabetes had always been about food choices with my family and all of us trying to be fitter and generally taking care of ourselves together. Coronavirus changed that so much with it focusing on me and my body and would could go wrong with it and how I was suddenly in a different category of needing medical support.”* (Participant 8)

The exploration of difference emerged when thinking about the intersections of need and resultant inequity:

> *“I live in a flat, I get state pension, I don't have any savings I live right in the middle of [the city]. So, I said during a lockdown, how could I exercise? All the markets were shut so I had to go… well my son had to go to proper supermarkets and pay twice as much for everything. The foods I normally eat were harder to find but it would have been different if it it's where I normally shopped or if I had a garden or if I lived in the country but I couldn't go anywhere I couldn't eat what I wanted so it is harder to stay in control.”* (Participant 5)

The experiences described shed light on the intricate interplay between the subjective experiences and the broader social, economic and structural factors that influenced PwT2DMs' ability to maintain their health during the COVID-19 lockdowns. Participants spoke of a range of socio-economic factors including geography and living space, dependence on state pensions and government support, absence of savings potentially limiting access to resources and opportunities for maintaining wellbeing. The pandemic exacerbated these disparities and unveiled the inequities affecting the individual's ability to exercise and access affordable, healthy food options. These challenges highlight the structural barriers, such as urban living conditions and limited financial resources that might impede a person's capacity to effectively manage their health. This perspective emphasises that participant experiences are embedded within a broader context including social policies, public health measures and systemic inequalities that shape the reality of their experiences.

Participants spoke of a *"shift in identity"* (participant 8) in relation to other identities held and, for the first time, through the lens of their diagnosis of diabetes during COVID-19. These nuanced insights into professional identity shifts and transformations reflecting the influences of socially constructed norms, biases and stereotypes. The imposition of certain labels and constructions led to feelings of isolation and alienation as participants struggled with the complexities of these multiple and intersecting identities including feelings of confinement and reductivism:

> *"I don't think of myself as being a 'diabetic' at work. I'm just a mentor. But then I was a 'diabetic mentor,' it was like a new position. Then it was 'oh, you're a Black diabetic mentor.' Then it was like 'you're a Black, diabetic, overweight' or whatever. Not me, but you know...it must have been so hard to have all these labels all of a sudden and not know what to do with them."* (Participant 12)

> *"The summary [paperwork] after my 'Return to Work' meeting was hilarious 'cause you could see my supervisor had googled the proper names for the diabetes and blood pressure, you know. But I wasn't keen that all that was*

> *written down at work now and what she felt was important and what wasn't about me."* (Participant 3)

3.4.2. Lens of Shame and Stigma

In addition to the shifts in identity described on an idiosyncratic basis, participants spoke of their experiences of being positioned differently in the context of 'being diabetic' by wider social discourses during the COVID-19 pandemic. This subtheme highlights descriptions of *"bringing diabetes on yourself"* (Participant 3) with an emerging discourse around those who *"didn't look after themselves before COVID becoming part of the problem."* (Participant 6). This was further described as *"being part of the blame and shame game"* (Participant 7) that constituted the wider discourses locating the problem of diabetes and threat of diabetes within the individual:

> *"I think people have kind of judged diabetes. As I say, I think I think diabetes, the type 2, is seen a bit as a kind of a, well, you've obviously got that because of your poor lifestyle sort of thing, yeah?"* (Participant 12)

> *"…at work with people saying about hospitals being full because people hadn't looked after themselves"* (Participant 4)

Six of the participants described the interplay between the subjective experience of shame and the wider social discourses of blame that appeared to be amplified during the COVID-19 pandemic. These individual fears of being judged or stigmatised for becoming severely unwell were described as being rooted in the societal attitudes and beliefs about personal responsibility and self-care. Feelings of shame and fear of blame spoke of an internalised pressure to maintain an image of a responsible citizen and 'patient' which may have been more heightened at a time of global crisis when society may be more inclined to assign blame and to seek scapegoats to help navigate feelings of uncertainty and fear:

> *"As I'm talking now, it's horrible thinking that if I got really unwell, and people knew it was because I had diabetes, they might think that it's because I didn't look after myself. That it was on me, really."* (Participant 3)

Participants spoke of the attitudes that emerged during the course of the pandemic relating to T1DM vs T2DM. Experiences were located in the differences articulated through social media whilst negotiating the differences between social distancing and social isolation following the 17th March 2020 government announcement:

> *"The way we [type 2 diabetics] were seen compared to type one changed overnight even though the government hadn't said anything other than 'diabetes.' You saw the shift in attitude towards us and it being about fault and being able to do something about our diabetes."* (Participant 13)

> *"The gloves came off even with other people with diabetes going at each other because there was no solid information and all the Type 1 diabetics got all the support and Type 2 were just taking chunks out of each other."* (Participant 3)

The internal conflicts were described elsewhere with participants spoke of *"one-upmanship"* (Participant 2) and a *"need to point the finger"* (Participant 10) when sharing experiences of online forums and self-help groups. Four participants described feeling *"excluded"* (Participant 2, 6, 7, 11) as a consequence of having T2DM compared to T1DM from within the diabetic community to which they belonged.

Participants felt that their diabetes contributed to them *"becoming a liability"* (Participant 13) with their *"diabetes suddenly mattering more because of the impact it might have on others."* (Participant 1) Descriptions of hesitancy rooted in altruistic concern were expressed with a desire not to burden healthcare professionals when participants positioned their diabetes as self-inflicted:

> *"I didn't really want to go and add to the problem I suppose because I was one of the 'pre-morbid' or having pre-existing conditions so you already felt like a problem just by existing."* (Participant 4)

> *“The whole system was up in the air and I guess you wanted to not add to the load even though you were being told that you were in the danger zone.”* (Participant 11)

Related to the sense of duty was the description of those with COVID-19 having a greater need and that the *“manageable aspects of diabetes”* (Participant 9) being seen as a lesser priority with one participant seeking advice from a private GP service provided through their employer as to not *“add to the demands on COVID stretched NHS services.”* (Participant 8)

Participants spoke to processes of conflation between T2DM and obesity and the synonymous relationship between the two constructs:

> *“They were really singling diabetics out. But I wondered if it's because you couldn't call someone fat or obese but it was OK to call them diabetic.”* (Participant 9)

The range of participant experiences speaking to obesity’s relationship to T2DM was striking and almost universally discussed. Furthermore, the role of obesity and visibility of illness, vulnerability and self-management weaves through a number of the thematic threads in this analysis. In the context of shame and stigma, participants spoke broadly about media representations of those with existing health conditions (including diabetes) and interpretations of messages as interpreted by news outlets:

> *“The Mail talked about getting fit with your hour of exercise and they had a little box about diabetes really saying that diabetics are all fat. Not directly, but done in a way that it was meant to help us fight COVID.’* (Participant 4)

Participants shared their initial thoughts and responses to becoming aware of this research with reference to experiences of *“hostility and blame”* (Participant 9) in July 2020 with the Government’s ‘Better Health’ strategy (2020) announced in the wake of then Prime Minister, Boris Johnson’s admission to hospital with COVID-19. These observations appeared to speak to the narratives around COVID-19 being influenced by power dynamics, vested interests and socio-political contexts that served to reinforce negative stereotypes and perpetuate inequalities within both healthcare systems and wider society. Furthermore, the role of media and prominent political figures was once again brought to the fore in relation to their role in shaping and disseminating these discourses as well as the potential for their influence to ripple through families and communities permeating everyday conversations thus impacting on individuals on an individual level potentially exacerbating feelings of guilt, shame and self-doubt:

> *"…overweight people were being blamed for other people dying. I don't think that was fair and I really noticed that whenever they talked in the press about diabetes, they were talking about overweight people.'* (Participant 10)
>
> *"The lose weight to save lives slogan was a big talking point in my family when Boris got his trainer and became the poster-boy for COVID-19. The story about people who were unhealthy blocking beds felt cruel and shifted the problem onto us out of nowhere and I could notice the impact it had on those around me with what was coming out. And it was all about managing the diabetes. Sorting out the diabetes."* (Participant 2)

3.5. Theme Two : Becoming [In]visible

This theme explores the way in which PwT2DM experienced the various ways of firstly being *"forced into the spotlight"* (Participant 5) during the earliest stages of the emerging COVID-19 pandemic before needing, as time went on, to make sense of the *"constantly changing"* (Participant 1) and *"inconsistent"* (Participant 3 & 7) positioning of PwT2DM. This negotiation was discussed in reference to spheres of interpersonal relationships, employment settings and dynamics with healthcare providers and the consequences of these interactions.

3.5.1. Disclosure : Coming Out

Participants shared that they felt, due to the pandemic, as though they *"had to come out as a diabetic for the first time"* (Participant 10) with *"people suddenly needing know all my business whether I want them to or not."* (Participant 1) This was understood as being *“a necessity with the pandemic forcing me to tell people”* (Participant 4) as a consequence of taking precautionary measures i.e. shielding. This led to participants describing having *“no option but to be open about my status as Type 2”* (Participant 6). The framing of diabetes as being a ‘status’ was further demonstrated by participants sharing feelings of forced disclosure:

> *“In the office, it’s like I’m wearing a T-shirt with ‘DIABETIC’ written in capital neon letters”* (Participant 3)

> *“You had no option but to tell people why they needed to [take a COVID] test before seeing you and to ask them to disclose whether <u>they</u> were positive or negative.”* (Participant 10)

> *“I ended up feeling a lot of guilt because the person I was living with then had to sort of make sure they were shielding and had to then communicate to those around them why, and I think that added a level of anxiety and I guess, yeah, feeling really uncomfortable around it because I knew that it was partially due to my own and my behaviours that I was in that position and it was now on them, too.”* (Participant 9)

This transactional sharing of health status was described as amplifying and negotiating the attitudes and perspectives of others in day-to-day interactions with *“everyone apparently having an opinion on how I should manage my health.”* (Participant 12)

> *“If we’re doing cakes at work or someone’s passing around the Krispy Cremes, I know I shouldn’t go there. And I can make that decision on my own. But now it’s become everyone else’s business with ‘do you want one?’ coming with a bit of an attitude since everyone now knows why I had to work remotely for longer”* (Participant 4)

Whilst diabetes had been described by participants as being *“quite a private matter”* (Participant 2) that was considered something that *“was not really something you talked about with friends and family in my culture”* (Participant 5), participants spoke of having to find a language to explain their relationship to their diabetes to others for the first time:

> *"I had been used to only speaking with my nurse about diabetes every few months in private and they do the talking. Now I am expected to talk about it with strangers like line managers and HR people and explain my illness which feels uncomfortable when I wouldn't even speak with my family about it."* (Participant 11)

This necessary disclosure also resulted in experiences of humiliation and degradation when navigating participation in conventional social activities. Participants spoke of comments made that appear to reveal deeply rooted issues in societal norms and values that have historically stigmatised people with diabetes. These comments not only demonstrated to participants a lack of understanding and empathy but also the internalisation of prejudiced beliefs and attitudes that appear to have exacerbated these challenges with participants feeling compelled to disclose their diabetes to mitigate risk thus potentially exposing themselves to further discrimination and stigmatisation.

> *"One guy, quite a close friend who I mentioned the diabetes to, made a joke about my having 'a limp dick' and it threw me as I hadn't thought of people talking about diabetics this way."* (Participant 13)

> *"I wanted to run and hide after they took my order and my daughter called me out in front of everyone for ordering rice and naan bread. And she'd never done it before so it came as a shock. It was our first meal out when we could on the '[Eat Out to Help Out]'. She said it's because COVID made her worry about my health and I couldn't eat bread as a diabetic and desserts were not allowed which is not true. Then everyone started giving me their opinion on what they thought about my diabetes."* (Participant 6)

By disclosing their condition – or having it done for them – participants described feeling forced to navigate the complex terrain of societal expectations and biases often at the expense of their own emotional wellbeing. In contrast, one participant described the value of being able to talk openly about their diabetes and to receive the experiences of others as both normalising and containing during a time that was *"full of uncertainty and worry*." (Participant 4)

> *"I can't say that anyone at work knew about my diabetes – not for any particular reason – but there wasn't a need until I had to do the risk assessment with my line manager. So I've not had an opportunity to talk about it 'til now. And I've found it helpful knowing there are two other people in the team and hearing their thoughts on it all."* (Participant 8)

3.5.2. The Dance : Negotiating Vulnerability

Universally, and without exception, participants spoke of the experience of receiving official government guidance and the renegotiation around risk and perceived vulnerability throughout the unfolding pandemic. Participants spoke of *"being in the driving seat one minute and the passenger seat the next"* (Participant 3). One participant described being *"led on a not-very-merry dance"* (Participant 11) through a landscape of change and revision led by a *"conveyer belt"* (Participant 2) of politicians and policy makers. The implications of this change of directive were shared in light of employee rights, access to priority services and access to care. Participants described the relationship between individual experiences, structural constraints and social discourses in the context of the pandemic and feeling caught in a web of systemic pressures that forced them to make difficult decisions regarding their health, safety and financial wellbeing. These decisions being shaped by the larger socio-political landscape that informs public opinion, employer policies and government mandates. The inconsistencies and conflicting messages from these entities appeared to create a context of uncertainty and anxiety, all driven by the dominant societal discourses that prioritise productivity and economic contributions over personal health and wellbeing. Furthermore, the role of power dynamics in the healthcare system and its intersection with social determinants of health were described with participants speaking of the struggle to assert their needs and secure necessary accommodations, reflective of systemic biases and inequalities that disproportionately affect those with chronic health conditions:

> *“Talk about mixed messages! One minute you're told stay safe and then the next minute my boss is asking when I'm going back. I'm type two I've got high blood pressure I've been isolating and then I get a call from HR to say that they need to take my pay down because I've been off for more than 12 weeks and you try and explain it to your employer but you don't have a leg to stand on because the government messaging changes every five minutes.’*
> (Participant 9)

> *“I control my diabetes with my diet and exercise and the hour [exercise] restriction was one thing but trying to keep on top of diet when you were told you were vulnerable and shielding but Morrisons said diabetes wasn’t on their list for priority shopping and even the chemist wasn’t sure if they could deliver my medications as it wasn’t clear if I was on the vulnerable list or not.’*
> (Participant 1)

Making sense of, and reconciling, the language and terms used in both official communications and from daily briefings was described as leading to confusion and resultant feelings of isolation with no clear path for obtaining definitive advice. These multiple, overlapping terms and categories in public health messaging and media can further exacerbate confusion and ambiguity in absence of clear, consistent and accurate communication to facilitate a more comprehensive understanding of vulnerability and risk among individuals with diabetes and other health conditions. Moreover, this confusion may not merely be as a result of inadequate information but also reflects the broader epistemological and ontological challenges in the context of the pandemic. As researchers and healthcare professionals grappled with the rapidly evolving nature of COVID-19, the fluidity and uncertainty inherent in the scientific processes shared through public health messaging can trickle down to the individual level, shaping their perceptions and experiences of vulnerability. Additionally, participants spoke of the emotional and psychological dimensions of labels around vulnerability. These emotional dimensions are influenced by societal discourses around vulnerability, personal responsibility and the expectations placed upon individuals to navigate their health and wellbeing during the pandemic with participants feeling disempowered and marginalised as they struggled to assert their needs and rights in the face of systemic barriers and constraints.

> *"I wasn't sure if I was meant to get a letter about shielding as my sister in the next county did and I didn't. And when I tried to ask the GP, they said you're not in the high risk category, then they said I was in the high risk category but not that extremely vulnerable category and I couldn't make head nor tail of what all these words meant for me."* (Participant 1)

> *"To this day, I'm still not actually sure whether I was vulnerable or why. Noone has been able to tell me what it means definitively."* (Participant 3)

> *"I had to look it up before talking to you because one minute you are vulnerable, then clinically vulnerable, then clinically extremely vulnerable and then very high risk. What's the difference? And then it was locked down, isolation, shielding, isolating? Can you tell me : is shielding different to isolating?"* (Participant 9)

Participants described the impact of government and public health information being shared from different sources : specifically, from government politicians versus scientists and the resultant impact on where guidance was sought as the pandemic went on:

> *"I focused in on Chris Whitty and [Patrick Vallance] in place of my GP, who I couldn't get hold of. They became a bit of a lifeline for me because I could follow their advice and felt human."* (Participant 6)

The significance of trusted public health figures was described in shaping personal experiences and responses during a crisis including the reliance on scientific figures as a "lifeline" suggesting that these public figures offered much-needed guidance in the face of limited access to their primary healthcare provider. The use of the word "human" implies that the participant sought not only accurate and reliable information but also a sense of empathy and understanding, which might have been lacking in other sources of information more readily available to participants at the time.

In contrast, the more insidious side of public health messaging was described with one participant perceiving the government's approach as an exercise in power and control highlighting the theatrical and performative aspects of the messaging, which was understood to assert authority rather than prioritise public wellbeing and safety. Furthermore descriptions of disillusionment with the government's communication and its potential to disengage and disempower the public, including those with diabetes were made with messaging being understood as manipulative or disingenuous leading to distrust and disengagement:

> *“The podiums and flags and the War Rooms just showed how much the politicians loved the power. It was interesting to see how comfortable the government was telling everyone what to do. But because they took the lead, everyone else gave up trying.”* (Participant 12)

The descriptions of the displacement of autonomy and decision making away from healthcare providers towards politicians and advisors in light of government mandate and legislation led to experiences of *“frustration and bewilderment”* (Participant 4) at traditional figures of healthcare provision *“appearing to have their hands tied and just shrugging their shoulders”* (Participant 1) when trying to understand the cause and impact of declared vulnerability.

Participants described the turn away from labels of vulnerability. The ubiquitous use of language orientated around being perceived as ‘vulnerable’ was understood to be *“othering and really stigmatising”* (Participant 3) with descriptions of vulnerability being synonymous with processes of both aging and infantilisation. This was most explicitly, though not universally, observed by male participants who shared frustration with the assertion of labels of vulnerability. In this context, the rejection of vulnerability labels by male participants can be seen as an attempt to maintain their hegemonic masculinity, which discourages the expression of emotions and vulnerabilities traditionally associated with weakness (Connell & Messerschmidt, 2005):

> *“If there was a pecking list of vulnerability as diabetic, or if they draw a waiting list of vulnerability, I would say put me down at a lower level for within my*

> *category because there are people who are gonna need the help and assistance a lot more than I am because I'm quite capable of taking care of myself."* (Participant 7)

> *"Don't call me vulnerable. My daughters call me a rottweiler so make sense of that!"* (Participant 10)

The language around a 'pecking list' or 'category' appears to speak to the rapid processes of categorisation and classification during the pandemic as a way of organising around risk both in terms of risk from disease but also risk to others. In contrast, other participants described vulnerability as a homogenising process that failed to recognise other identities held that appeared to contradict the label of vulnerability:

> *"I didn't like receiving the letter. I understand they had to send them to everyone but being in your late 30s, with three children, a full time job, you know, and then you're told you're vulnerable…"* (Participant 9)

> *"You told me I'm vulnerable but what bit of me was vulnerable? Vulnerable is all weak voice and trembling. How vulnerable? Says who? And why? My mum was vulnerable because she was in a care home and no one could see her, but how was I?"* (Participant 11)

> *"I don't think it's a helpful word actually. You were just vulnerable. You weren't a vulnerable man or woman or child or a specific group. Just vulnerable."* (Participant 3)

Participants also described the wider impact of labels of vulnerability when navigating existing mental health needs and the ramifications of being identified as someone who may need to isolate themselves as a consequence of a *"new layer of vulnerability"* (Participant 1). Whilst this 'layer' was intended to provide insulation, it led to feelings of isolation, reduced self-efficacy and an increased reliance on others thus inadvertently contributing to an exacerbation of existing psychological distress. Indeed, the concept of vulnerability – one that is not an absolute but rather a relational and dynamic construct – and influenced by wider institutional policies resulted in labelling that may lead to marginalisation thus reinforcing stigmatisation. Furthermore, the positioning of vulnerability was described as failing to recognise participants' unique circumstances and coping mechanisms during the pandemic with employment described by three participants as crucial to maintaining positive emotional wellbeing and disregards the need for a more nuanced and context specific understanding of vulnerability and its ramifications:

> *"I've struggled with my mental health for quite a few years now and work has been a major part of staying in a good headspace. When I was told I was on the vulnerable list it seems that they didn't realise that not being able to work made me more vulnerable than having diabetes."* (Participant 1)

The relationship to employment, aside of the emotional impact of losing the structure of employment in terms of ones wellbeing, was explored in the context of practical considerations for employers and the ramifications for employees as a consequence:

> *"I install air conditioning units and my line manager, when I told him that I got this letter, just said that he didn't know if he'd be able to get insurance if I was vulnerable. I'm not sure it all properly been thought through when these letters got sent out to those of us that were still working. That felt like a much bigger impact on me, as in losing my income, than the diabetes did."* (Participant 3)

Participants described their existing relationship with the notion of vulnerability and how such language had been operationalised in different contexts pre-pandemic. These descriptions went on to explore the intersections of vulnerability and the recognition that it is not an inherent characteristic of individuals but is, in fact, shaped by social, economic and political factors with participants speaking to age, ethnicity, existing health conditions and living conditions. Participants spoke of frustration over seemingly arbitrary categorisations of vulnerability with public health messaging being experienced as haphazard with notions of 'straw-clutching' speaking to a lack of consideration over diverse experiences resulting in mistrust and ambivalence towards the authorities responsible for public health messaging. The struggle to meaningfully discern which aspects of their identity and life circumstances were being considered combined with the singular gesture of a letter of correspondence underscored feelings of abandonment, disregard and neglect despite being considered part of a vulnerable group.

> *“Ohh, and if they're Indian, they're more vulnerable. And if they're this, and if they're, ‘if they're homosexual,’ if they're, you know, it was, like, clutch at straws just to try it. I think there was a lack of thought here.*’ (Participant 4)

> *“I’m Black, I have proper depression and I’m disabled with my foot and I live on my own in a flat in [London] so I am on all the lists and diabetes is the next on the list now. Like now I am vulnerable. But, you know, I don’t see myself as the government do.”* (Participant 12)

> *“I couldn’t tell which bits of me were the vulnerable because I’m a porter so around people or because I’m Brown or because I’m diabetic or because I have asthma or because my 68 year old mother lives with us. So which is it? It’s like a big net but who’s looking after me if I am vulnerable? I got a letter and nothing else.”* (Participant 2)

3.6. Theme Three : Going it Alone

This theme explored the way in which participants spoke about self-determination and, out of necessity, becoming autonomous in decision making around the management of their T2DM. This was as a consequence of a loss of social connection alongside *“the shutters coming down”* (Participant 4) when attempting to access healthcare provision. This resulted in feelings of being deprioritised whilst assimilating to differences in how particular conditions may be impacted by COVID-19. As a result, participants spoke about *“going it alone”* (Participant 11) in seeking advice and exercising greater autonomy in terms of self-monitoring. Having *“come out as diabetic”* (Participant 1) earlier in the pandemic, as restrictions began to lift, the *“new-found resource of family and friends”* (Participant 10) was described as facilitating a legacy of behavioural change and ongoing self-management.

3.6.1. Out of Sight, Out of Mind

Participants described the experience of losing the monitoring and regulatory mechanisms at play as a consequence of social and familial connections that were taken away due to COVID-19 social restrictions. Participants spoke of *"any symptom changes or differences in appearance"* becoming harder to notice as a consequence of *"living a completely different way of life during the pandemic"* (Participant 5). This included reference to changes in physical activity, sleep patterns and proximity to toilet facilities that would previously have served as a marker of symptom changes in T2DM. Some individuals thought that before the pandemic, the identification, alteration and intensity of any outward physical symptoms may have been more evident through self-perception and the observations of others. Interruptions of regular activities, work routines or a loss of social circles were described as affecting the ability to recognise symptoms in different ways.

> *"I normally check my [blood] sugars if I started to feel tired or was unable to concentrate at work. And remote working meant I didn't go very far and I was not moving very much and getting out of bed much later and not socialising."* (Participant 11)

The introduction of support bubbles in June 2020 was described as helping to mitigate against some of the effects of PwT2DM not being *"properly seen"* (Participant 8) during the earlier stages of the pandemic with one participant sharing a vivid memory of their granddaughter visiting after a four-month absence. This experience appears to highlight the importance of the immediate family and social network in supporting processes of self-monitoring, for example, with foot care:

> *"She walked in and the first thing she said to me was that I was walking differently. And my son said the same. I didn't notice myself but it was just a shock to hear…because it was news to me."* (Participant 13)

Participants shared the challenges around gaining access to healthcare providers generally with cancellations of routine diabetes health checks, long wait times to speak to a member of the GP practice, poor appointment availability and new triage processes that further limited access to care and information. One participant's experience spoke to a manifestation of systemic weaknesses including resource constraints, inadequate structure of remote care delivery and a lack of preparedness identifying specific causal powers and generative mechanisms such as the closure of facilities. The struggles to access care were not solely as a result of personal circumstance but emerged though the broader context of the healthcare system and society's response to the pandemic highlighting the need to consider the interconnected nature of individual experiences and the wider social structures that shape them.

> *"I was trying to speak to doctors at the time, cause they was all shut down and it was, well, I'll say nearly impossible. We used e-mail and the tablets and things that I have cause how was I gonna get my prescription? Now it's via the e-mail, so that wasn't too bad, but if we wanted to speak to them about anything it was impossible. So we might, if we were lucky, we might get call back from them in anything from 2 weeks to 5 weeks or depending how busy they were but the surgery virtually shut down when the first wave of COVID came in".* (Participant 10)

Universal descriptions of a shift towards consultations being offered via tele-medicine spoke, again, to the absence of the in-person experience which, in the case of T2DM also removed the *"simple observations about looking well or noticing things about me that I might not have noticed myself"* (Participant 3) in addition to the previously described loss of social perspectives on change.

> *"I was happy to just chat on the telephone with the diabetes nurse at first. She was very supportive and that. But she always looked at my hands and my eyes and feet when she was chatting to me and couldn't do that of course."* (Participant 7)

Participants described feeling deprioritised in the face of other underlying health conditions including respiratory, cardiovascular and immunocompromised PwT2DM appearing to be considered less deserving of support:

> *“I felt that It wasn't banned from going [to the GP], but I just felt that I wasn't allowed to because they possibly wouldn't give any information. I think they've probably thought that diabetes was something that wasn't high on their priority as strokes or cancer and everything else.”* (Participant 10)

This was also described in the context of T1DM vs T2DM and the variance in access to care experienced:

> *“I’d not considered being a different [type 2] diabetic before until COVID and the pharmacist wasn’t willing to deliver my medication because I wasn’t a Type 1 diabetic. And the [GP] receptionist was of the same opinion.”* (Participant 13)

The descriptions of barriers to access and limitations in access to adequate diabetes healthcare was ascribed to a general feelings of *“paralysis in the system and in society”* (Participant 1) with *“all of life slamming the brakes on.”* This was further conceptualised as *“a sort of global stuckness”* (Participant 4):

> *“When everything came to a halt, you sort of gave up after a while even trying to get any sort of an answer and whatever health conditions you were living with were sort of overshadowed by COVID and the other things wrong took a back seat. For me and, I guess, everyone else.”* (Participant 8)

3.6.2. Becoming my own Medic

In addition to the practical barriers detailed above, participants described wider political and social discourses that served to moderate attitudes towards seeking support. Participants identified communications from media, government and healthcare services early on in the pandemic as setting the stage for fostering a sense of *“responsibility”* (Participant 9) among UK residents. News coverage and visuals of *“overrun hospital wards and dreadful pictures of swamped hospitals”* (Participant 10) were described as heightening concerns that healthcare systems were overburdened and assistance was unavailable.

> *"… words like 'war zones' and Boris would look right down the camera telling us we 'must do this' and 'must do that' like Blitz spirit normally followed by the news showing people on ventilators in intensive care."* (Participant 7)

> *"Seeing the hospitals I just decided that I would step up so I wouldn't be another one of those obese people in the bed. I didn't want to be that person or another daily statistic."* (Participant 4)

These accounts of feeling burdened were attributed to COVID-19 becoming, out of necessity, the main focus with the perception that utilising resources and clinicians' time would be *"selfish knowing that the health service was already on its knees."* (Participant 12) The conceptualisation of T2DM as something *"self-induced"* (Participant 2) and managed *"mainly on your own"* (Participant 3) spoke to the assumptions around PwT2DM being able to manage their symptoms and disease progression autonomously:

> *"Diabetes, type 2 anyway, is seen as a 'lifestyle disease' and one where you can take control of that lifestyle. So managing COVID and all the controls and restrictions felt pretty straightforward for me. When everything was going to shit, I was able to switch gear quite easily."* (Participant 3)

The relationship between T2DM being a *"control disease"* and COVID-19 *"being all about restrictions and rules"* (participant 9) was discussed in the context of self-monitoring and regulation of behaviours:

> *"Everything was about control with COVID you couldn't go out…he had to do this…she had to do that…you had to wash your hands had to wear a mask. But because I only recently found out about the diabetes, I feel like I've become quite good at being in control of change in the way I do things."* (Participant 10)

> *"I feel like what wasn't spoken about was how diabetes is like all about self-management. It's all about self-care and you've got to be really involved in managing it on your own. It wasn't thought about and that's become a big part*

> *of how I think about my health generally but I know I'm different I just think COVID really made you aware of needing to take control because otherwise you were someone else's problem."* (Participant 2)

These observations describe the locus of control being located within the individual and away from wider social systems. As a consequence, participants described accounts of engaging in enhanced self-monitoring and self-management including adjustments to diet and exercise as well as an uptake in use of self-monitoring blood glucose devices:

> *"I joked with my wife that the Amazon driver must have thought we were setting up a GP practice or were playing doctors and nurses with all the kit we got in.'* (Participant 7)

A number of participants spoke of *"becoming my own nurse"* (Participant 12) by replacing lost feet-health checks, podiatry appointments and eye checks with methods of recording observations to provide continuity of care. Furthermore, this was described as helpful for determining thresholds of change that might warrant input from healthcare professionals:

> *"I've journaled before to help with anxiety. So decided to do the same but always kept a section on any physical changes I'd noticed and emailed it to my practice on patientaccess. And I had a way of looking at any changes in case I needed advice over the phone"* (Participant 9)

These thresholds of symptoms were described in the context of illnesses both related and unrelated to T2DM. However, the bar which had to be met after which to seek help was described as being higher during the pandemic. This was attributed to both *"not really being unwell enough to justify taking up resources"* (Participant 2) and, in the context of advertised vulnerability of PwT2DM, the risk of catching COVID-19 by attending clinical environments appeared to play a part in seeking help and decision making during the pandemic:

> *"And I had an appointment with the doctor because of my waterworks but didn't go because the waiting room would have been full of it. And then she [wants to] sends me off to the hospital for tests and next thing you know I am covered. No. No. I didn't unlock the door for days at a time."* (Participant 13)

This process of shielding may have, paradoxically, in trying to establish protections of 'vulnerable' individual's health, contributed to a process of isolation and anxiety around seeking help and advice from healthcare providers.

The necessity of seeking assistance for complicated T2DM health issues during the pandemic was described as having negative effect on numerous participants' emotional wellbeing. This was associated with coping with uncertainty, receiving a new diagnosis of diabetes that increased their clinical susceptibility to COVID-19, feeling guilty for *"demanding unnecessarily"* (Participant 5) of services, regretting or *"blaming myself for not seeking help sooner"* (Participant 2) and worsening pre-existing mental health challenges:

> *"Only finding out about getting diabetes in December and then the lockdown a few months later drove my mood down, down. One thing on top of another, on top of another and my mood was worse than ever before. I was angry and worrying, worrying all the time."* (Participant 12)

> *"I feel it has sort of made everything bigger than I already had on my plate. I felt a bit sorry for myself. But, by the summer, I realised that it suited, the lockdown, it suited me and I felt much better in myself not having to be out. Is that strange?"* (Participant 10)

The theme of managing independently emerged as a prominent and recurring pattern throughout the interviews with participants describing an increase in connectivity through isolation and resilience through existing experiences of being alone and living independently:

> *"I've been going it alone for many years so COVID didn't make much of an impact on me at all apart from odd visits gone. You know, I spoke with more*

> *people online, because everyone used the internet to chat so felt I was talking with people more than ever."* (Participant 7)

The extent of this experience of independence ranged from successfully *"fending for myself"* (Participant 12) to feeling *"cut adrift"* (Participant 13). Some individuals expressed an intense perception of being *"deserted"* (Participant 5) and *"overlooked"* (Participant 3; Participant 6). This feeling was ascribed to both the enforced isolation and the endeavours focused on tackling and prioritising COVID-19-related matters.

Ongoing behavioural changes were also described, including persistent worries into the future about contributing to already increased waiting lists and backlog issues in relation to provision of care. One participant, diagnosed with T2DM only six months before the pandemic, recounted their reluctance to seek assistance more than a year after the pandemic's onset, in spite of the severity of their condition.

> *"I see myself repeating it now, even though I know I am struggling to get the diabetes under control because I eat to feel better about things, and I still can't get my head around going to the doctor because I haven't done anything to turn things around. And even though we were told to 'wake-up' with COVID, it's about not wanting to add to the huge waiting lists. Now it's coming into winter, too"* (Participant 9)

Nonetheless, participants also exhibited a sense of agency amidst the alterations and obstacles encountered, as one individual shared: *"It's getting easier to sort of navigate a way forward now"* (Participant 12). Adaptive strategies were undertaken to help manage the changes experienced, such as attending pharmacies during less busy hours, relying on alternative support sources (e.g., online groups and forums via Diabetes UK) or making remote appointments more manageable (by recording sessions and sharing remote links allowing family members to join). Additionally, there were stories of resilience and increased self-assurance:

> *"Back to that control thing, I feel more in control of the diabetes now than ever before. Big change. And I know now where to get advice from and how to be in the driving seat. I'm not the only one, if you look on the forum. It's such a*

good community and it is because of COVID for sure. The ideas, *there's new medications and recipes and it's not from the GP but from each other."* (Participant 3)

4. DISCUSSION

4.1. Overview

In this chapter, the findings are discussed in connection with the research questions and, where available, the pre-existing literature. This is followed by an examination of the study's research and clinical implications, as well as a critical evaluation.

4.2. Summary of Study Aims and Findings

Previous research has suggested that T2DM, under ‘normal’ conditions, can pose a significant and negative impact on quality of life (Fisher et al., 2015). Combined with the psychosocial consequences of the COVID-19 pandemic, however, an amplification of the burden of those psychosocial challenges for individuals living with T2DM may occur (Joenson et al., 2020). The role of government and public health communication strategies and media discourses can further lead to adverse psychological responses (Généreux et al., 2021). The current research expands on emerging literature by asking the research questions :

- What are impacts of – and responses to – public and government messaging around T2DM and COVID-19?

- How do people with T2DM describe help seeking in the context of COVID-19?

Thematic Analysis was employed, from which arose three main themes, each of which were arrived at to help with better understanding the experiences of PwT2DM during the COVID-19 pandemic : ‘Diabetes Identity’, ‘Becoming [In]visible’ and ‘Going It Alone’. Without presuming that the researcher’s interpretation of participant experiences is a universal truth, the intent of the discussion is to explore the experiences of PwT2DM navigating the COVID-19 pandemic and the resultant barriers to help-seeking.

4.2.1. What are the impacts of – and responses to – public and government messaging around T2DM and COVID-19?

4.2.1.1. Unmasking and Reclaiming Identity

Participants described navigating a sudden renegotiation in their relationship with diabetes as a consequence of processes of categorisation and subsequent de/prioritisation in government messaging. This was captured by two subthemes: 'Dehomogenising Diabetes' and 'Negotiating Vulnerability.' Governments sought to create a sense of shared identity during the pandemic by crafting messages that emphasised group membership and strengthened social norms (Cruwys, 2020). Early research into the shared experience of the UK population during the COVID-19 pandemic's outbreak depicted a strengthening of collective identity among individuals confronting a mutual fate in a time of crisis, subsequently leading to enhanced collective resilience and acts of solidarity (Berrocal et al., 2021). Additionally, a tendency to assist and support in-group members (Levine et al., 2005) fostered an 'all in this together' mentality, culminating in the establishment of social norms centred around reciprocal aid and collaborative support. However, participants in this research described the individual differences and needs of specific populations as being overlooked by political leaders alienating subgroups as a consequence of creating norms that could not be adhered to by all of society, the effect of this being the inadvertent homogenisation of the experiences of PwT2DM.

As a consequence of being inadvertently positioned outside of the collective social norm, participants felt compelled to 'come out' about their T2DM diagnosis, primarily as a selfless act for others' safety rather than their own. PwT2DM were located in a subgroup deemed 'vulnerable' due to their heightened likelihood of experiencing complications from the virus, increasing the probability of requiring hospitalisation or other medical interventions (Callender et al., 2020). This placed additional strain on an already overburdened healthcare system, making diabetics feel as though they were a burden at the expense of others seeking care. The combination of government-imposed restrictions to protect those at risk, such as isolation and shielding, with the need to manage T2DM through regular exercise, diet and self-management techniques, created a 'no-win' situation for PwT2DM. This led to increased feelings of futility, shame and embarrassment in living with a 'lifestyle disease' they perceived as self-inflicted but lacked resources to manage during the pandemic.

4.2.1.2. Unveiling Shame and Stigma

Participants described experiencing shame and diabetes-related stigma, characterised by perceived exclusion, rejection, blame, stereotyping and status loss. These experiences align with existing literature that investigates the role of shame and stigma in PwT2DM outside of pandemic contexts (Archer, 2014; Browne et al., 2013) suggesting that the pandemic may have exacerbated the stigma and shame experienced by this group. Indeed participants described moving from a state of strategising opportunities for managing behaviours during the pandemic to a state of global devaluation as a consequence of government messaging, in which they blamed their personality and experienced hopelessness choosing not to talk about their difficulties and disconnecting from others resulting in further isolation and loss of emotional and practical resource as described in the pre-pandemic context by Browne and colleagues (2013). Contrary to expectations derived from the existing literature, however, participants revealed a unique experience specific to the context of the pandemic, where their diabetes became a newly experienced threat to others. This novel perspective emerged as PwT2DM were seen as a risk to the healthcare system in terms of requiring additional resources and, consequently, became conceptualised as a risk to otherwise healthy individuals who may require the same system. Those with T2DM were perceived as 'at fault' due to the disease being often framed as a lifestyle disease, where changes can be made to reduce its impact as described by Sauchelli and colleagues (2021).

This perception was exacerbated by the UK government's health plan (Department of Health and Social Care, 2020) promoting the narrative of 'Lose Weight, Save The NHS' alongside stigmatising discourses around diabetes in both tabloids and broadsheets, where people with diabetes and/or obesity were construed in fatalistic terms and held responsible for the strain on the country's healthcare system. Participants highlighted that press media coverage largely relied on discourses around autonomy and individual responsibility, framing their diabetes as a fundamental moral flaw. This aligns with research by Broom and Whittaker (2004) whose study argued that whilst control over ones diabetes denotes power and agency, loss of control – by contrast - signals chaos and a resultant moral failure. Individuals were thus made responsible for eradicating their diabetes through diet modifications and exercise to reduce illness risk (from contracting COVID-19) by, as far as participants knew, lowering blood sugar levels (Peimani, Nasli-Esfahani & Sadeghi, 2020). The narrative of personal responsibility, attributing PwT2DM with challenges faced by the NHS during COVID-19, not only aligns with the prevalent ideology of neoliberalism within the United Kingdom, it equally illustrates the connection between tabloids, right-leaning media and their endorsement of individualistic values. While stigmatising portrayals of PwT2DM in the media may not be exclusively attributed to the pandemic (Hunt et al., 2022) participants' experiences of media representations during this period indicate a heightened level of stigmatising discourse. Individuals with T2DM have not only been held accountable for their own health complications, but they have also been shouldered with the responsibility for an overburdened healthcare system in the midst of the most acute public health crisis in recent history. This social stigma, originating from the assignment of blame, may engender additional negative attitudes towards PwT2DM and result in the internalisation of shame within the context of the COVID-19 pandemic (Diabetes UK, 2020). This aligns with Joenson et al. (2020), who found that shifts in government messaging on vulnerability led to concerns of social stigma, rather than physical health risk, among participants.

In contrast, broadsheets, especially those leaning politically left, tended to discuss the causes of underlying health conditions in relation to broader socio-political factors and assigned responsibility to entities like the government, food suppliers, and a strained healthcare system. The pandemic offered media outlets a chance to explore and critique the impact of racial and ethnic health disparities on obesity and other related health issues. This approach could potentially increase the public's critical awareness of the social factors influencing health, serving as an effective counter-narrative to the personal responsibility narrative. However, this opportunity seems to have been inadequately utilised by the tabloid press and, to a smaller extent, right-leaning broadsheets, as the link between racial and ethnic disparities in diabetes prevalence and COVID-19 mortality rates was rarely reported in relation to the larger structural inequalities that likely contribute to these disparities (Sowden et al., 2021).

4.2.1.3. Revaluating 'Vulnerability'

While certain participants viewed shielding and social distancing measures for the clinically vulnerable as benevolent acts of safeguarding and care, offering information, practical support and validation of their disease's severity, others emphasised the considerable influence of language and discourses surrounding the concept of 'vulnerability.' This encompassed all their other identities, disclosed their disease status more broadly than desired, and/or categorised them as distinct (occasionally perceived as having lesser value) from the 'normal' population. Such findings have been discussed in research that explores the lessons from HIV research and the balance between COVID-19 public health responses and stigma reduction (Logie & Turan, 2020). The language of 'vulnerability' can oversimplify complex issues by reducing them to simple dichotomies such as strong vs weak or empowered vs vulnerable. This approach obscures the complex interplay of social, economic and political factors that contribute to 'vulnerability' with Katz and colleagues (2020) identifying the concealment of the structural nature of public health problems that can serve the political function of obscuring power relationships and inhibiting the discussion of transformational change.

By reinforcing power imbalances between groups, the language of 'vulnerability' supports paternalistic attitudes and behaviours that limit autonomy and agency (Ferreira et al., 2021). In the context of T2DM, this may undermine participants' confidence in self-management and their ability to think freely and independently about their needs. Ultimately, this language stigmatises already marginalised groups by perpetuating stereotypes and negative attitudes resulting in a portrayal of diabetics as potentially overweight, lazy and ultimately responsible for their condition. Previous research by Feagin and Bennefield (2014) identified that vague and euphemistic descriptive language orientated around appearance of illnesses can result in unarticulated assumptions that obscure the realities of wider inter-related structural factors including colonisation, racism and economic exploitation in relation to health inequality.

Participant experiences of government and NHS England messaging focusing solely on individual behaviours in managing T2DM overlooks critical structural factors that significantly contribute to the disease's existing prevalence and management (Adu et al., 2019). These factors point to socioeconomic factors, as lower-income communities already face higher rates of T2DM due to limitations in access to nutritious food, safe spaces for physical exercise and multiple systemic barriers to adequate healthcare provision. The language of vulnerability in media and government discourses often overlooks these systemic issues, focusing on individual behaviours without acknowledging the barriers that many people face in accessing appropriate healthcare and education. This results in reinforcing a narrative of personal failure rather than addressing underlying social determinants of health (Marmot & Bell, 2019). Additionally, employing terms like 'vulnerable' without clear definitions, a solid theoretical foundation and thoughtful examination of power disparities influencing public health practices might unintentionally suggest that vulnerability is partly, or mainly, an innate characteristic resulting from group affiliation, rather than external factors. This perspective on 'vulnerability' as an intrinsic state implies that it is the affected populations that require adaptation or adjustments in their 'vulnerable' conditions while maintaining the status quo. Therefore, it is essential to approach the concept of vulnerability with clarity and a thorough understanding of the underlying systemic factors.

4.2.1.4. Intersectional Invisibility

Participants discussed the impact of being identified in government messaging as simultaneously belonging to various marginalised groups during the pandemic (e.g. age, ethnicity, disability) in addition to their T2DM diagnosis. Intersectionality theory (Crenshaw, 1989) posts that these multiple identities intersect to create experiences of marginalisation, privilege and discrimination. Public health messaging, according to participant experiences, failed to adequately address the specific needs, experiences and risks of individuals who held intersecting marginalised identities leading to descriptions of invisibility and misprioritisation with inadequate provision of support inadvertently exacerbating existing disparities leading to increased risk of harm as a consequence of the COVID-19 pandemic. This is consistent with research identifying structural and cultural racism during the pandemic (Razai et al., 2021) and reinforced by findings from the COVID-19 Impact Enquiry Report (The Health Foundation, 2021).

Furthermore, individuals belonging to stigmatised social groups often experience heightened stress due to their minoritised position in society (Meyer, 2003). The stigma process identified in minority stress literature, including internalised negative self-concept, rejection anxiety, social hypervigilance and concealment behaviours, aligns with patterns of shame and shame avoidance (Flentje et al., 2020). The COVID-19 pandemic presented a unique situation where these stresses were intensified beyond those experienced by the non-stigmatised population, primarily due to social and structural forces, including government enforced lockdowns and imposed isolation, rather than an individual's inherent identity or behaviour. These stressors may be further amplified by the reduction of social support due to a lack of understanding from within immediate support networks and increased instances of bias, hate crime or social exclusion as a result of discrimination and prejudice toward marginalised groups (Abrams, 2010) This highlights the need for future public health efforts to consider the complex interplay of multiple stigmatised identities and their impact on individuals' wellbeing.

4.2.2. How do people with T2DM describe help-seeking in the context of COVID-19?

Participants spoke to the variety and intricacy of processes and factors influencing their help-seeking efforts in managing T2DM during the pandemic, as well as the extended implications of these help-seeking experiences.

During the pandemic, various socio-contextual factors underwent substantial transformations encompassing aspects such as social disconnection, alterations in life situations and shifts at societal, environmental and individual levels. Considering these changes, and in the absence of an established body of relevant and contemporary research, the Capability, Opportunity, Motivation, and Behaviour (COM-B) model (Michie et al., 2011) serves as a useful framework for contextualising the current study's findings. Considering the context-specific barriers reported across all theoretical domains of the model, the challenges of seeking help during the pandemic can be comprehended as stemming from both intrinsic factors within the individual and extrinsic factors originating outside the individual that are likely to impede the process of help-seeking in the context of the extrinsic aspects determined by the COVID-19 pandemic. The experiences of participants, as described in the data, have been summarised in table 2 below.

Table 2 : The COM-B Framework applied to research findings

CAPABILITY	OPPORTUNITY	MOTIVATION
Psychological	*Physical*	*Reflective*
• Lack of consistent information and evidence re interaction between T2DM and COVID-19 • Length of diagnosis and relationship to self-management	• Limited access to healthy and affordable food • Access to shops • Time restrictions on exercise and shopping	• Beliefs around risk of contagion • Beliefs relating to existing demands and pressures on NHS • Developing habits around social distancing and shielding
Physical	*Social*	*Automatic*
• Ability to get to resources (incl. healthcare) with remote care provision	• Experiences of stigma and shame • Becoming a risk to others and violating social norms	• Anxiety in context of pandemic • Low mood as a consequence of isolation

In the present study, it was observed that participants with a more recent diagnosis of T2DM and limited experience in self-management, necessitated by the pandemic, described less proficiency gained through practice. Consequently, these individuals reported a need for reassurance and guidance in managing their condition due to the disruption of routine care. Conversely, participants with a longer history of diabetes appeared to adapt more readily to the changes describing a lesser need to seek help and support with self-management. Research examining the association between the duration of diagnosis and adherence to self-management protocols, as well as receptiveness to diabetes education, has shown that recently diagnosed patients display greater adherence compared to those diagnosed for more than a year (Brown et al., 2016; Ko et al., 2012). This phenomenon has been widely discussed in the literature and is attributed to a potential ‘diabetes burnout,’ resulting from the perpetual threat of severe complications or persistent symptoms experienced throughout PwDs’ lives (Abdoli et al., 2020).

These findings highlight the need for individualised and tailored approaches that take into account the duration of diagnosis when designing interventions as argued for in pre-pandemic contexts by Grabowski and colleagues (2020). Newly diagnosed PwT2DM may necessitate additional physical and psychological educational support, while those with a longer duration might require targeted interventions to address poor adherence to self-management practices in the absence of routine and familiar resources. This is particularly important in light of the psychological burden imposed by chronic illness, underscoring the significance of addressing these unique needs to optimise the overall management of T2DM.

Participants noted a decline in both physical and social opportunities for assessing changes in visible differences and accessing valuable resources due to mandatory lockdowns, protective measures and limited healthcare availability. As described by Sauchelli and colleagues (2021), public health messages highlighting an overburdened health service and the potential danger of contracting the virus appeared to decrease the reflective motivation for seeking help during the pandemic. Anxiety-provoking media messages may have also contributed to a reduction in automatic motivation to ask for assistance. Social distancing further restricted participants' psychological capacity to evaluate changes with their T2DM and solicit support, resulting from both perceived and actual deficits in social support, as well as diminished physical opportunities to engage with the NHS and request help due to the cancellation of routine appointments.

Social isolation surfaced as a recurrent subtheme in participants' experiences, significantly impacting their ability to detect physical changes, evaluate the scale of change, and make decisions related to help-seeking. The consequences of isolation and the significance of social infrastructure in promoting help-seeking behaviour have been illustrated in studies examining the experiences of individuals with chronic pain during the COVID-19 pandemic (Amja et al., 2021). In this study, participants indicated a considerable reduction in social interactions during the pandemic, resulting in a significant loss of help-seeking opportunities. This effect was further intensified for individuals under shielding protocols and designated as "clinically extremely vulnerable" (Hodgson et al., 2021).

While discussing alterations in life circumstances during the pandemic, participants reflected on the changes in opportunity and capability associated with recognising symptom variations. These changes contributed to a delay in the identification of evolving symptoms (e.g., increased fatigue, unquenched thirst, frequent urination) and consequently, a postponement in seeking help. This observation aligns with a previous study that identified shifts in symptom awareness when daily routines were disrupted, prompting individuals to seek help when their routines were interrupted (Hall et al., 2015). However, the considerable and unparalleled upheaval of everyday life due to COVID-19 led to a less distinct sense of normal routine, subsequently limiting opportunities for symptom recognition.

The swift transition from pre-pandemic social norms to new and unprecedented norms, including social distancing, influenced participants' experiences of uncertainty concerning help-seeking in terms of both timing and opportunity (Leventhal et al., 2016). The rapidly transformed landscape of NHS healthcare services at the primary care level diminished physical opportunities to find help thus intensifying individuals' feelings of uncertainty, leading to confusion when attempting to access suitable pathways towards help.

Primary healthcare services, government and national media communication and messaging were recognised as vital factors, especially concerning decision-making processes regarding help-seeking with symptom management. This appears to have resulted in cognitive disonance with individuals becoming increasingly worried in relation to the management of their T2DM whilst simultaneously experiencing apprehension regarding help-seeking and the potential consequences of pursuing assistance. This situation seemingly resulted in the adoption of 'disengagement beliefs' (Bandura et al., 1996) which may alleviate the psychological unease created as a consequence of the disonance.

Consistent with prior research (Niksic et al., 2015; O'Connor et al., 2021), the present study identified crucial help-seeking barriers, such as concerns about consuming healthcare professionals' time, straining limited healthcare resources and accessing healthcare services. Beliefs about becoming a burden were also voiced elsewhere in the literature in a cross-sectional population survey examining help-seeking behaviours around potential cancer symptoms during the formative months of the pandemic (Quinn-Scoggins et al., 2021). Pre-pandemic research on help-seeking barriers has demonstrated that UK adults are more likely to express worry about 'bothering the doctor' in comparison to individuals in other high-income countries (Cromme et al., 2016). However, in this study, generational differences, as opposed to cultural differences, were evident with older participants describing fear of becoming a burden to overstretched services and younger participants describing frustration and resentment towards poor service provision when attempting to seek help.

4.3. Implications and Recommendations

The findings suggest that the impact of public messaging during the COVID-19 pandemic had both positive and negative implications for individuals PwT2DM. Whilst communications supported and encouraged increased awareness and vigilance around risk from severe illness thus encouraging extra precautions to avoid infection, this came at a cost in terms of the toll taken on emotional wellbeing, experiences of shame and stigma and a perceived loss of resource : both social and in terms of healthcare provision. This was shown to have had an impact on help-seeking behaviour with a newfound reliance on remote healthcare, shielding guidance limiting existing peer support and withdrawal from services for fear of becoming an additional burden. These experiences were moderated by the various additional identities held by participants. The following subsections expand upon these findings considering the implications for policy design, practice and future research.

4.3.1. Policy

In formulating policy recommendations and guidance for healthcare access during future pandemics or similar situations, it is essential that policymakers acknowledge the obstacles faced by PwT2DM in evaluating and self-regulating novel and ambiguous symptoms, regardless of their expertise in disease management. Participants' accounts reveal a multitude of factors influencing their appraisal and help-seeking behaviours, which are, as a consequence, shaped by broader contextual elements (Michie et al., 2020). As such, public health initiatives must strategically address and target these modifiable determinants to effectively promote help-seeking in T2DM management.

In future, the implementation of a stringent shielding directive must be accompanied by provisions that facilitate effortless access to - and direction towards - reliable information. This will enable individuals to discern when venturing out is officially advised, alleviating feelings of guilt or concerns of imposing a burden. While succinct and unambiguous messaging is paramount during a pandemic, it is equally crucial to incorporate explicit guidance on when, where and how to seek assistance for diabetes management, thereby fostering social acceptance and reassurance (Ramkisson et al., 2017). In addition, it is crucial to emphasise the need for transparent guidance on avenues for addressing concerns about symptom change and obtaining advice when routine healthcare services are disrupted or halted amidst fluctuating circumstances. Equally important is the provision of explicit instructions on what to anticipate when accessing healthcare services during a pandemic, which can bolster patients' psychological capability and reassure them to seek necessary assistance.

To foster confidence in promptly contacting primary care providers, it is essential to offer clear, consistent information from a reliable source that delineates alterations in general practitioner (GP) practice procedures and outlines expectations. This approach should also address concerns regarding healthcare system capacity and infection control measures within hospital settings. To counterbalance potential sensationalism in the news coverage of future pandemics or public health emergencies, the use of trustworthy narratives from PwT2DM emphasising positive outcomes can play a significant role in reframing experiences and promoting engagement in primary care appointments and routine clinical monitoring.

It is vital to propose that public health messaging promotes regular check-ins with friends and family members who may be isolating due to health risks. This can facilitate symptom recognition, management and appraisal whilst mitigating feelings of loneliness. Additionally, such messaging should clearly delineate the target population by establishing their social identity (Neville et al., 2021). To encourage help-seeking and behavioural change, these messages ought to reinforce rather than contradict the target group's identity, which can be achieved by invoking higher-order group values, focusing on a sense of communal support and unity (Drury et al., 2020).

It is vital to co-create public health campaigns with individuals possessing first-hand experience with T2DM to ensure comprehensibility, simplicity and practical guidance. Interventions should be developed in collaboration with those with lived experience rather than by external organisations alone, such as governments, thus promoting community engagement in the establishment of new norms (Wallerstein & Duran, 2010). Health and communication messaging must be tailored to specific contexts and linguistic requirements, utilising culturally adapted on and offline modes of information dissemination and exchange (Handtke et al., 2019). Moreover, evaluating the efficacy of campaigns and other interventions is crucial for ascertaining that messages are reaching diverse audiences and not exacerbating health disparities (Razai et al., 2021). To that end, it is important to note that the utilisation of language referring to 'vulnerability' can oversimplify intricate issues, reinforce power disparities and stigmatise already marginalised populations (Clark & Preto, 2018). Such discourses neglect crucial structural factors that impact the prevalence and management of the disease, consequently undermining the autonomy, agency and self-management of PwT2DM. Rectifying these deficiencies in public and government messaging is vital to enhancing support for PwT2DM and fostering a more inclusive and comprehensive understanding of the condition.

Communication strategies should strive to promote social cohesion while avoiding the inadvertent stigmatisation of any 'vulnerable' group. Decision makers ought to emphasise attributes such as resourcefulness, resilience, agency and strength. Furthermore, prioritising engagement mechanisms within affected communities is essential, particularly among those who - despite facing increased risks - may demonstrate robust political and social awareness as well as valuable experience and insights in collective organisation and coalition building.

It is important to recognise the interaction of multiple identities and the intensification of stressors in particular situations, which allows for a more comprehensive understanding of health disparities faced by affected individuals. This, in turn, fosters a more inclusive and supportive environment for all. It is crucial to consider the differential impact of various factors. An analysis of future public health emergenies that solely focuses on those with underlying conditions versus the healthy population may overlook or inadequately account for critical determinants such as age, geography, disability, race/ethnicity, migration/refugee status, social class and other structural conditions including unstable housing, employment and political or environmental stressors (Caron & Adegboye, 2021; Razai et al., 2021)

A nuanced understanding of underlying health conditions, based on an intersectional analysis rather than a single-axis approach, is necessary. An intersectional lens centres marginalised identities and examines the influence these have on an individual's relationship with systems of power (Jones et al., 2022). This can be accomplished by disaggregating T2DM data to identify risk factors that vary across different groups. Consequently, this results in policy design that supports healthcare providers at the local level in adhering to protocols that facilitate personalised medicine. By ensuring a person-centred approach with a risk-based model that differentiates factors such as age, co-morbidity, barriers to care and the presence of community resources, more tailored and effective care can be provided.

4.3.2. Practice

The findings of this study underscore the uneven distribution of adequate healthcare support during the pandemic, which can be attributed to participants' varying degrees of technological literacy and availability, as well as the diverse systems implemented at the practice level. Locally, services should proactively counteract messages of non-availability and promote accessible pathways. This can be achieved by incorporating remote care delivery preventatively rather than reactively, integrating both remote and in-person care into mainstream practice to support potential future transitions in the context of social distancing and isolation measures for PwT2DM. This approach offers the opportunity for advanced screening of technical confidence, literacy and access to technology, thereby increasing awareness of the technological divide. Nonetheless, studies have shown that employing technology for medical appointments can exacerbate existing language barriers, hinder the establishment of rapport and diminish GPs' capacity to identify safeguarding concerns (Wieringa et al., 2022).

In cases where individuals have access to the necessary technology and privacy, integrating primary, secondary and community remote healthcare systems and platforms can support practice effects when engaging with services during and outside of shielding situations. Employing remote delivery methods that are simple, culturally sensitive, well-practiced, integrated and protective of patient data is crucial and attendance to robust safeguarding procedures must remain at the centre of design and implementation.

In terms of healthcare provision, the connections between social status, discrimination, diabetes as a discernible or undetectable disability, choices about revealing one's condition and resilience are crucial factors influencing healthcare provision and the interaction between healthcare professionals and their patients. Healthcare providers should recognise their own social location, including its advantages and limitations, in order to foster humility and invite PwT2DM to share their experiences and expertise (Wadhwa & Mahant, 2022). Recognising the intricacies of one's identity and its impact on the way individuals cope with and handle diabetes can promote more candid discussions about disclosure and stigma, while also facilitating bespoke recommendations and support.

A significant observation from this research was that all participants experienced challenges with their wellbeing at some juncture during the pandemic, regardless of their previous history of mental health difficulties. This struggle was particularly emphasised by participants who lived alone compared to those who lived with family members or partners. Participants identified various factors contributing to their wellbeing challenges, including persistent feelings of unsafety and fear of mortality, the pandemic's prolonged duration, social media usage and confinement at home. All participants mentioned the winter months as being especially challenging to manage and shared strategies for coping with their wellbeing, such as informal social support, escapism and finding a sense of purpose. These findings indicate that professionals working with this demographic should carry out regular mental health check-ins over time, irrespective of initial reports of 'wellness’. Extra care should be taken during winter months, as a number of participants identified this period as more challenging with services considering the provision of supplementary resources and support during this time. Furthermore, since many participants found comfort in connecting with others who shared similar health challenges, services could facilitate peer-to-peer communication and support for these groups and signpost to existing third sector provision in this area.

As services continue to revert to their pre-pandemic operations, the enduring effects of individuals' help-seeking experiences and decision-making during pandemic restrictions will persist in influencing aspects like mental health and future help-seeking behaviour. Healthcare providers need to be aware of this during patient interactions guaranteeing fairness, continuity and equitable access through open communication. Patient involvement and feedback mechanisms should be central to the local-level provision of care in shaping service design.

4.3.3. Research

To the best of the researcher's knowledge, this study represents the first exploration of the perspectives of PwT2DM on public health messaging and the consequent impact on help-seeking behaviours during the COVID-19 pandemic in the UK. Given the rapid expansion of research on the biomedical aspects of the interactions between T2DM and the pandemic over the past three years, it is essential to amplify the voices of those directly affected by T2DM in order to inform future research. As discussed in section 1.3.1, although research studies often conflate the experiences of individuals with either T1DM or T2DM, examining other aspects of identity that intersect with underlying health conditions can deepen our understanding of barriers to seeking help and the reception of public health messaging. By employing an intersectional approach, future research can shed light and deconstruct the complexities of minds and bodies as sites where intersecting forms of oppression converge, generating new knowledge and more holistic representations of marginalised experiences. This, in turn, will facilitate a greater understanding of health and more comprehensive solutions (J. Abrams et al., 2020). A syndemic approach could be beneficial in helping to understand how social inequities contribute to the production of multiple, interacting health issues, including both T2DM and COVID-19 (Boes et al., 2021). To reduce barriers to research participation, innovative, online and community-based strategies can involve those most impacted by COVID-19, including capturing the perspectives of healthcare providers delivering care to individuals with T2DM in light of their role in shame and stigma reduction. To that end, future directions to complement the findings of this study would hope to explore the experiences of healthcare workers in primary care in delivering supportive interventions for individuals with T2DM during the pandemic and, indeed, to explore the legacy it has had on service design and provision.

Furthermore, the unexpected, but welcomed, findings to emerge in relation to help-seeking in the context of COVID-19 was the legacy of change as a consequence of living through the pandemic with a focus on emerging autonomy and a demonstration of improved self-efficacy and self-determination with management of T2DM. It will be important for future research to explore through, for example, idiographic means, a rich exploration of the ways in which the pandemic experience may have contributed to a renegotiation in self-care practices and the ways in which the legacy of change has been sustained or otherwise. This approach accommodates the challenges of making sense of pre, during and post measurements of self-efficacy and changes in help-seeking behaviours in absence of baseline measures and retrospective data but serves to capitalise and meaningfully build upon these original research findings.

This study's findings should contribute to the development of real and measurable changes within services, not only in the context of the pandemic but also in addressing existing inadequacies and inequalities that the pandemic has exposed. Research into the experiences of specific groups during the pandemic should not focus solely on prevention in the context of future global health events, but also on uncovering pre-existing challenges and opportunities for improving care provision.

This necessitates the development of robust and concrete recommendations to enhance current and future communication strategies that account for the sociocultural aspects of large-scale outbreaks. Capturing the experiences of those who lived through this critical moment in history is crucial, and this research should be conducted with a sense of urgency and commitment.

Clinical psychology, with its interdisciplinary and international context, offers a valuable framework for addressing these issues. This field encompasses a wide range of content and methodology expertise including public health, health promotion, psychosocial and behavioural health, risk and crisis communication and discourse analysis. This diverse skill set allows for the integration of multiple perspectives and methodologies, as well as the identification of effective, tailored approaches that promote thoughtful health-related interventions both during and outside of global health events.

4.4. Critical Review

The following critical review is guided by Northcote's (2012) principals assessing the extent to which it is contributory, rigorous, defensible, credible and affective. Further strengths and limitations are also discussed.

4.4.1. Contributory

This study has achieved its aims of furthering our understanding of the ways in which public health messaging was experienced by PwT2DM along with descriptions of help-seeking in the context of the COVID-19 pandemic. The value of this study lies not only in its relevance to the COVID-19 pandemic but also in its contribution to the existing literature. While there has been extensive research on COVID-19, there has been minimal investigation into the pandemic's impact on individuals with underlying health conditions. Although some of the current findings corroborated existing literature, the primary focus of the research enriched the current literature in several ways by emphasising the unique ways in which the pandemic affected this particular group. Examples include the impact of language and labels around clinical vulnerability, the complex interactions between 'shielding' protocols and seeking support from healthcare providers during the pandemic and the self-imposed restrictions on help-seeking as a consequence of media narratives of NHS overwhelm leading to feelings of shame. Of note, this study has drawn attention to the experiences of those intersectionally marginalised, highlighting the unique impact the pandemic has had on those whose experiences are often unseen.

4.4.2. Rigorous (in conduct)

The data collection and analysis was systematic and conducted in fidelity with Braun and Clarke’s (2006) six stage approach to reflective thematic analysis. The researcher was dedicated to prioritising the experiences of participants by providing them the chance to express what mattered to them. Data collection was participant-driven, and minimal prompts were incorporated into the interview schedule, enabling participants to guide the conversation. A deliberate effort was made to address the diversity of experiences and the complexity contained therein through extensive engagement with multiple iterations of the data. To offer a coherent and transparent representation of the research, the methodological approach (Section 2) and results (Section 3) delineate the processes involved in research design, data collection and analysis. Each stage of the analysis is provided in the appendices and extracts of coded participant transcripts and the researcher’s reflective journal are contained within.

4.4.3. Defensible (in design)

The way in which the research design attends to the research question is outlined in section 2.2 and evidences the coherence between the aim of the study and the epistomological position and methods employed. Moreover, section 4.3 evidence the success of the design in answering the research question.

4.4.4. Credible (in claim)

The research findings demonstrate meaningful coherence (Tracy, 2010) with the research questions initially developed at being answered through the data collected and the through the extensive process of (re)constructing themes. The claims made by the research are borne from the data and align with both the findings of previously conducted research and in line with the ontological and epistemological position of the researcher.

4.4.5. Affective (in nature)

Considering the subject matter of the research, it is highly likely that the reader has had their own experiences with the COVID-19 pandemic. Consequently, the potential for transferability of the research findings is substantial. That is to say that it is the hope of the researcher that the careful selection of the quotes will have allowed the opportunity for the reader to ‘feel with’ the participants of the research. Furthermore, the research attends to the emotional elements of how the participants and the researcher engaged with the study. Participants affect and emotional experiences were attended to throughout chapter three and the researcher’s own emotional experience of the research process is attended to in section 4.5.

4.4.6. Limitations

Participation in the study was voluntary and participants self-selected. Despite attempts to be as inclusive as possible by promoting the study through various platforms (including online and print), employing broad inclusion criteria, and offering interviews online or via telephone, it is probable that only those who felt highly motivated and capable of discussing their T2DM chose to participate. This was potentially helpful for this study and may have meant that participants felt well informed about their diabetes and associated socio-political discourses, however it may not represent the views of PwT2DM more generally. Additionally, only two of the thirteen participants identifying as Black and two participants identifying as Asian is not a representative sample of those living with the burden of T2DM in the UK (Diabetes UK, 2021). This disproportion is problematic as the majority white perspectives are likely to be less alive to particular issues facing minoritised individuals, particularly in the context of barriers to care and hostile messaging in public health messaging due to underlying processes of Whiteness. Finally, interviews were conducted over a four-month period in late 2022, aiming to capture participants' experiences from the previous two years of the pandemic. This may have led to memory recall challenges and retrospective bias, causing participants to unconsciously reinterpret past events based on their perspectives during the interview and the pandemic's context. This limitation was considered throughout the process of both data collection (through member checking throughout interviews) and analysis by seeking detailed and contextualised descriptions of participants’ experiences to support credibility and transferability of findings.

4.5. Researcher Reflections

Reflexivity serves as a crucial element in conducting ethical research, necessitating attention to the experiences embedded within the research process, as these experiences impact both the participants' responses and the researcher's interpretations (Attia & Edge, 2017). Consequently, it is vital to examine the ways in which my position as the researcher may have influenced the shaping of this thesis, as well as how the thesis has, in turn, influenced me (Staley et al., 2017). Engaging in reflexivity requires researchers to critically evaluate their methodological choices and contemplate the implications of their epistemological stances on the research and the resulting knowledge (Dodgson, 2019).

Addressing the potential impact of my own research background on this thesis is crucial, as it is limited predominantly to quantitative and positivist methodologies and ontologies. My education, to date, has often been dismissive of qualitative approaches, a sentiment echoed by societal norms and institutional frameworks that prioritise 'gold standard' research. My initial exposure to epistemology, ontology and qualitative methodology occurred whilst studying at UEL, which inspired me to undertake qualitative research and acquire hands-on experience. As a novice in this domain, I experienced feelings of disorientation and confusion throughout the research process. My inexperience with qualitative approaches may have resulted in overlooking crucial aspects during the planning and development stages, as well as during data collection and analysis, which a more experienced qualitative researcher might have captured. Moreover, my historical quantitative bias may have led me to excessively seek patterns in the data rather than differences, potentially generalising findings inappropriately.

Upon reflecting on my growth and development as a researcher during this process, I would consider myself as taking a critical realist position (a Western philosophical stance) in place of my existing positivist stance and recognise, through the process of writing up the research, how that journey has been experienced on the page. By even proposing to research how those living with T2DM have experienced the pandemic, however, I have implicitly assumed that a T2DM diagnosis would have bearing on individuals' experiences of COVID-19 and that the diabetes, rather than other factors that have emerged out of this research such as socio-economic status, age, ethnicity or gender would be the primary catalyst behind their experiences.

Transitioning to an exploration of the ways in which the identities I hold, my beliefs and my own lived experience might have influenced this research, it is crucial to identify my own group memberships as a middle-aged white man, shaped by – and working within - a Western culture. The motivation for undertaking this research stemmed from my admiration for science, medicine and the pursuit of knowledge. The selection of my research area demonstrates the intention to draw on the inherent power afforded through the identities I hold and the groups to which I belong to create a platform for marginalised groups to be heard. As described earlier in the research process, the power I wielded while conducting this study might have impacted participants, who might have found it difficult to diverge significantly from my line of enquiry or to overtly declare that the ideas underpinning the research questions might be unconnected or my position in some way detrimental. To that end, as an employee of the NHS and as a provider of healthcare, I am aware that the opportunity to 'feedback' directly on experiences related to the system in which I work and upon which participants rely, is rare and may have resulted in participants feeling less able to state their position safely.

5. CONCLUSION

This study was the first UK based exploration of PwT2DM's experiences of government and public health messaging and help-seeking during the COVID-19 pandemic. The research has attempted to promote the voices of those living with T2DM and understand how their lives may have been impacted. The semi-structured interviews in this study illuminated the profound impact of the pandemic on PwT2DM, revealing the adaptations they made to ensure their own safety, the consequences of these adaptations and how public messaging around 'vulnerability', group membership and the ways in which an identity and responsibility for protection of the self became more about the protection of others. The research also underscored the importance of trust in relationships with services, the need for adequate provision for self-management, the impacts on their interpersonal relationships and resources and the influence of government and institutional responses to their experiences.

This thesis offers unique contributions as one of only a handful of qualitative studies exploring the experiences of people with underlying health during the pandemic and the only study, at the time of writing, focusing on PwT2DM. The findings emphasise the necessity of providing adequate support and guidance to those more susceptible to COVID-19 regarding safety measures and supporting their immediate networks to minimise additional risks. The research also highlights the importance of clear and thoughtful communication between public health bodies, professional bodies and patients advocating for a unified message, especially given the interconnected nature of patients through social media and third sector organisations, where conflicting information can cause confusion and concern. Moreover, the study underscores the need for taking a critical approach to both language and policy design when considering the impact of group identities, the loss of granular understandings when considering intersecting identities of marginalised groups and the ramifications of broad stroke terms including notions of 'vulnerability'.

Additional research is urgently warranted to explore the effects of the UK's transition to 'Living with COVID' on PwT2DM and the legacy on help-seeking, self-identity and emotional wellbeing. We cannot ignore the urgent need to understand the consequences of this change for those who are more susceptible to severe illness and death in the event of future pandemics, nor can we overlook how their lives might be altered into the future. It is our moral and ethical duty to hold governments and healthcare systems accountable, insisting that they rely on the research community's guidance to take immediate action to confront and overcome these disparities and to undertake meaningful action to protect those who may be harmed in the event of future public health emergencies. The legacy of the pandemic hinges on our collective determination to ensure that future generations do not suffer from the same concealed health inequalities.

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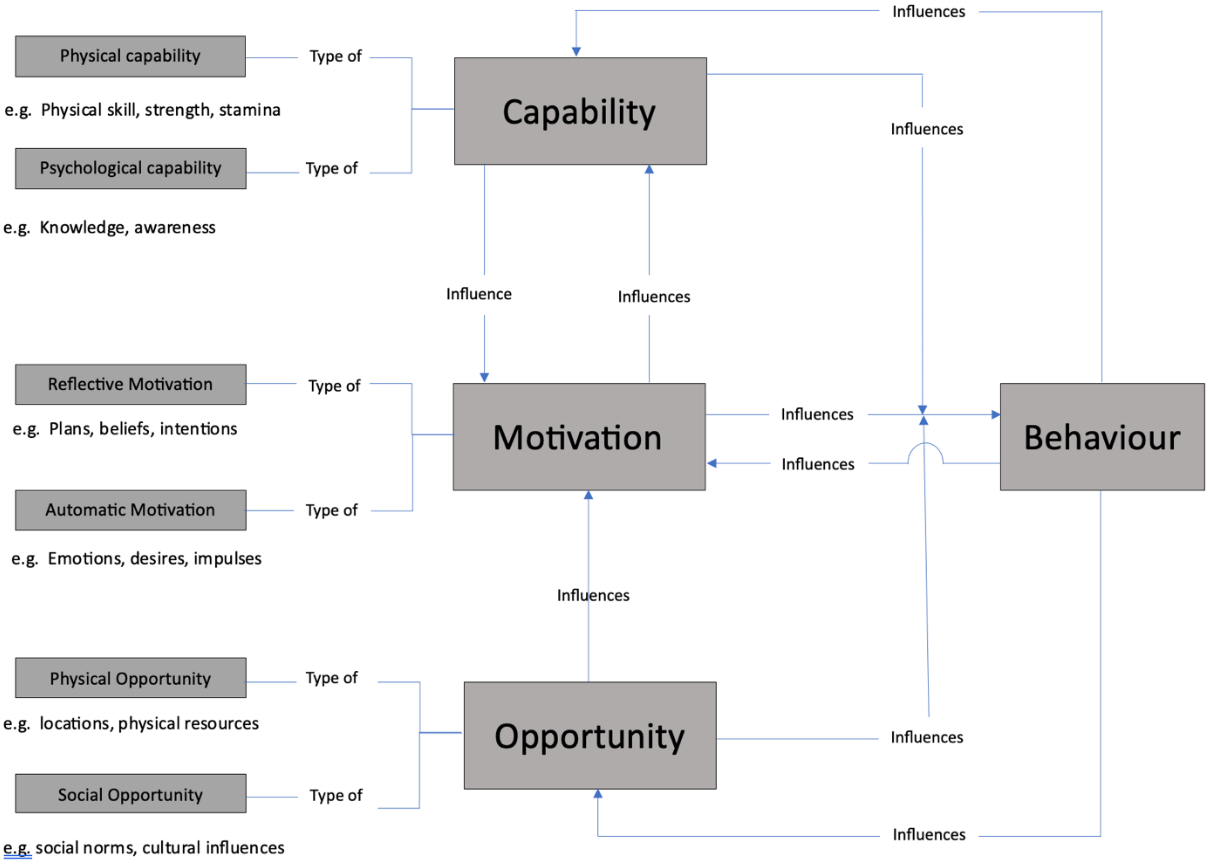
7. APPENDICIES

7.1. Appendix A: Visual Representation of the COM-B Model



Reproduced from West and Michie (2020)

Capability is an attribute of a person that together with opportunity makes a behaviour possible or facilitates it.

Opportunity is an attribute of an environmental system that together with capability makes a behaviour possible or facilitates it.

Motivation is an aggregate of mental processes that energise and direct behaviour

Behaviour is individual human activity that involves coordinated contraction of striated muscles controlled by the brain.

Physical capability is capability that involves a person's physique, and musculoskeletal functioning (e.g. balance and dexterity)

Psychological capability is capability that involves a person's mental functioning (e.g. understanding and memory).

Reflective motivation is motivation that involves conscious thought processes (e.g. plans and evaluations).

Automatic motivation is motivation that involves habitual, instinctive, drive-related, and affective processes (e.g. desires and habits).

Physical opportunity is opportunity that involves inanimate parts of the environmental system and time (e.g. financial and material resources).

Social opportunity is opportunity that involves other people and organisations (e.g. culture and social norms).

7.2. Appendix B : Literature Review

As a means of increasing both the sensitivity and specificity of the search itself, multiple electronic databases - including CINAHL, PsychINFO, SCOPUS and Google Scholar - were utilised, in line with the recommendations of MacLure, Paudyal and Stewart (2016).

Keywords were developed on the basis of Booth and colleagues' (2016) approach, and in order for further boost sensitivity and specificity, were combined with Boolean operators and truncation devices (Xiao and Watson, 2019). These were combined into a cyclical search syntax, in line with the recommendations of Peters and colleagues (2015), and can be seen below (Appendix X) :

The string search that was employed to search for relevant studies is as follows: 'UK' OR 'United Kingdom' AND 'Diabet*' AND 'Public Health' OR 'government' AND 'Coronavirus' OR 'COVID-19' OR 'SARS-CoV' OR 'pandemic' AND 'help seek*' OR 'healthcare seek*'

Following the deletion of duplicate papers from across the databases, inclusion and exclusion criteria were then utilised to screen for eligible papers.

Inclusion criteria :

- representing primary research of qualitative, quantitative or mixed methods that were focused on experiences relating to the COVID-19 pandemic
- that had a primary population of those with diabetes
- that was full text accessible.

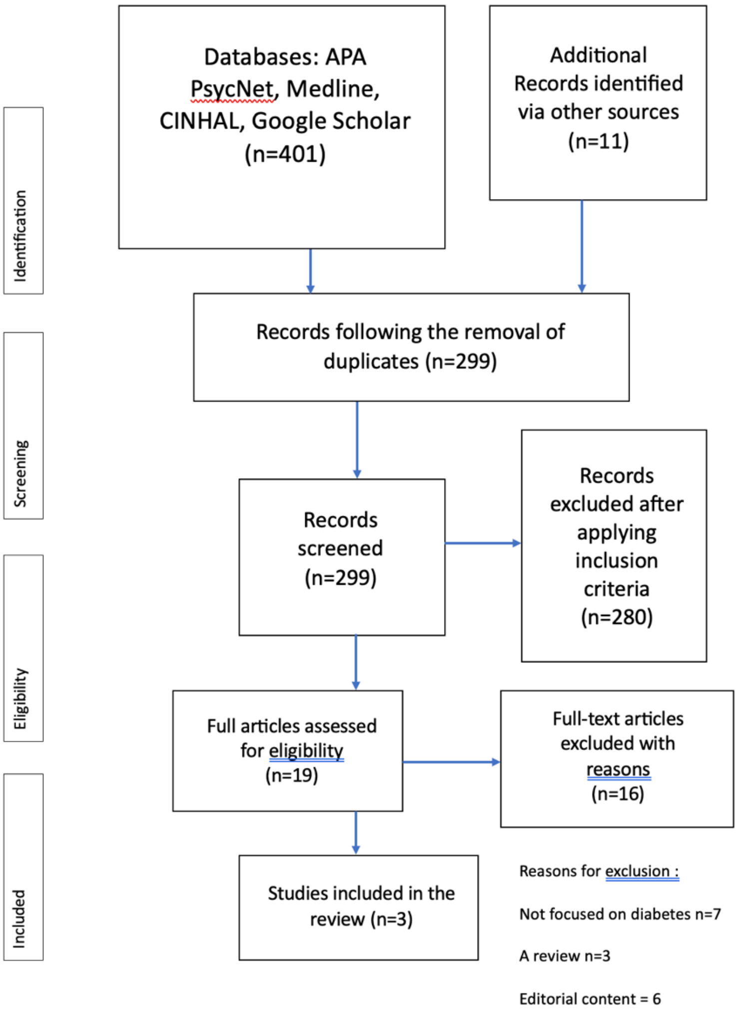
Exclusion criteria included :

- grey literature
- commentary, opinion pieces, editorial letters, theoretical papers with no data collection.
- papers focusing on specific subgroups i.e. healthworkers
- papers published prior to 2020

From the results, abstracts of all studies were read and references checked.

The selection process consisted of a three-stage strategy as recommended by Khan et al. (2003). The first step of this involved appraising the titles of all returned studies and excluding any papers which clearly did not relate to this review. This was followed by the abstracts of remaining papers being examined within the context of the above eligibility criteria, with a further edit taking place at the end of this. The final stage was to read the full text versions of each remaining paper, and select those that best fit the aims of the scoping review (Khan et al., 2003). A PRISMA concordant flow chart (Appendix X) details the outcomes of the above processes.

7.3. Appendix C : PRISMA Flow Chart



7.4. Appendix D : Ethics Application

UNIVERSITY OF EAST LONDON
School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL
FOR RESEARCH INVOLVING HUMAN PARTICIPANTS
(Updated October 2021)

FOR BSc RESEARCH;
MSc/MA RESEARCH;
PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

	Section 1 – Guidance on Completing the Application Form **(please read carefully)**
1.1	Before completing this application, please familiarise yourself with: ▪ British Psychological Society's Code of Ethics and Conduct ▪ UEL's Code of Practice for Research Ethics ▪ UEL's Research Data Management Policy ▪ UEL's Data Backup Policy
1.2	Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will look over your application and provide feedback.
1.3	When your application demonstrates a sound ethical protocol, your supervisor will submit it for review.
1.4	Your supervisor will let you know the outcome of your application. Recruitment and data collection must **NOT** commence until your ethics application has been approved, along with other approvals that may be necessary (see section 7).
1.5	Research in the NHS: ▪ If your research involves patients or service users of the NHS, their relatives or carers, as well as those in receipt of services provided under contract to the NHS, you will need to apply for HRA approval/NHS permission (through IRAS). You DO NOT need to apply to the School of Psychology for ethical clearance. ▪ Useful websites: (Tracy, 2010) ▪ If recruitment involves NHS staff via the NHS, an application will need to be submitted to the HRA in order to obtain R&D approval. This is in addition to separate

	approval via the R&D department of the NHS Trust involved in the research. UEL ethical approval will also be required. ▪ HRA/R&D approval is not required for research when NHS employees are not recruited directly through NHS lines of communication (UEL ethical approval is required). This means that NHS staff can participate in research without HRA approval when a student recruits via their own social/professional networks or through a professional body such as the BPS, for example. ▪ The School strongly discourages BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
1.6	If you require Disclosure Barring Service (DBS) clearance (see section 6), please request a DBS clearance form from the Hub, complete it fully, and return it to applicantchecks@uel.ac.uk. Once the form has been approved, you will be registered with GBG Online Disclosures and a registration email will be sent to you. Guidance for completing the online form is provided on the GBG website: https://fadv.onlinedisclosures.co.uk/Authentication/Login You may also find the following website to be a useful resource: https://www.gov.uk/government/organisations/disclosure-and-barring-service
1.7	Checklist, the following attachments should be included if appropriate: ▪ Study advertisement ▪ Participant Information Sheet (PIS) ▪ Participant Consent Form ▪ Participant Debrief Sheet ▪ Risk Assessment Form/Country-Specific Risk Assessment Form (see section 5) ▪ Permission from an external organisation (see section 7) ▪ Original and/or pre-existing questionnaire(s) and test(s) you intend to use ▪ Interview guide for qualitative studies ▪ Visual material(s) you intend showing participants

Section 2 – Your Details

2.1	**Your name:**	L M Wood
2.2	**Your supervisor's name:**	Dr. Trishna Patel
2.3	**Name(s) of additional UEL supervisors:**	Dr. Matthew Jones Chesters
		3rd supervisor (if applicable)
2.4	**Title of your programme:**	Professional Doctorate in Clinical Psychology
2.5	**UEL assignment submission date:**	22/05/2023
		Re-sit date (if applicable)

Section 3 – Project Details

Please give as much detail as necessary for a reviewer to be able to fully understand the nature and purpose of your research.		
3.1	**Study title:** Please note - If your study requires registration, the title inserted here must be the same as that on PhD Manager	Diabetic patient experiences of shame after acquiring COVID-19.
3.2	**Summary of study background and aims (using lay language):**	Whilst there has been a considerable body of research around the impact of the pandemic on those who had previously experienced mental health difficulties (and extensive research on the relationship between pre-morbid physical health conditions i.e., diabetes, hypertension, obesity) there is – to date – no research on the experiences of those individuals and the emotional impact of living through the pandemic. I would like to find out how do people with premorbid health conditions describe their experiences of help-seeking post-COVID and what are the impacts of - and responses to - messaging around premorbid health and COVID-19 i.e., government messaging, media and closer social systems. Specifically, as evidenced by research into previous pandemics (Ebola, Hepatitis B, HIV), messaging by public health bodies and wider social responses to COVID-19 are likely to generate stigma resulting in experiences of shame that can lead to poor mental health outcomes (Logie & Turan, 2020). These can stimulate feelings of worthlessness, inferiority and incompetence which, in turn, can lead to a need to hide and socially isolate (Miceli & Castelfranchi, 2018). The historical and emerging literature on shame experiences within the context of a pandemic alongside its role as a barrier to help-seeking in those with a diagnosis of DMT2 invite an exploration of the way those with pre-existing physical health complications may seek help both during acute illness and thereafter. This research could produce findings that may be of use when considering public health messaging alongside design around post-COVID mental health services in understanding barriers to access for those with co-morbid health difficulties.
3.3	**Research question(s):**	1) How do people with Diabetes Miletus Type 2 (DMT2) describe their experiences of having COVID-19? 2) How do people with DMT2 describe help-seeking in relation to COVID-19? 3) What are the impacts of - and responses to - messaging around premorbid health conditions during a Pandemic?

3.4	**Research design:**	A critical realist position will underpin the proposed research. In line with this epistemological position, it is proposed that a qualitative method (individual semi-structured interviews) will be used to address the research questions.
3.5	**Participants:** Include all relevant information including inclusion and exclusion criteria	To ensure the delivery of 'a new and richly textured understanding of experience' (Sandelowski, 1995) the study will seek semi-structured individual interviews with 8-12 participants in line with recommendations from Braun and Clarke (2013) with regards to achieving data saturation. Inclusion criteria : (1) participants will have acquired acute COVID-19 (confirmed with a positive COVID-19 test) (2) have a pre-existing diagnosis of DMT2 (3) be in the post-COVID phase of illness (4) be able to read study materials written in English (5) be able to converse in English without the need for an interpreter (6) be 18 years old and over. There are no further exclusion criteria.
3.6	**Recruitment strategy:** Provide as much detail as possible and include a backup plan if relevant	Participants will be recruited using purposive sampling. A recruitment advert will be distributed via social media support groups and UK online forums that have granted permission to post research advertisements. Permission will be sought again immediately before posting. These will include: (1) The Diabetes.co.uk Research Forum (2) Facebook 'Diabetes Support Group' (3) The Diabetic Lounge UK (4) Facebook UK Diabetes Forum (Type 2). Those interested in participating in the research will be invited to contact the researcher with any questions about the study, determine their eligibility and subsequently be provided with information, demographics and consent forms to be shared. A speculative date and time for the interview will be set pending participant review of forms.
3.7	**Measures, materials or equipment:** Provide detailed information, e.g., for measures, include scoring instructions, psychometric properties, if freely available, permissions required, etc.	Due to Covid-19, interviews will be conducted via Microsoft Teams via the UEL Teams Account assigned to the researcher. Interviews will be recorded on Microsoft Teams and will be auto-transcribed. The auto-transcriptions will be reviewed and edited by the researcher. Each participant will be given a participant number (in interview chronological order) and all identifiable information (e.g., names, job location, identifiable scenarios) anonymised in the transcripts. Personal data will be collected on consent forms (names) and prior to the interview (email address and/or telephone number). An interview schedule has been

		constructed following a consultation phase whilst shaping the research question and piloted to inform the current version (see appendix F).	
3.8	**Data collection:** Provide information on how data will be collected from the point of consent to debrief	**DATA WILL BE: ** Personal data collected on consent forms including name, email address and/or telephone number. Demographic data including age category, sex, ethnicity, length of diabetes diagnosis, country of residence (England, Wales, Scotland, Northern Island). Interview transcripts (in Microsoft Word format 8-12 participants). Interview recordings (in .mp3 format – 8-12 participants). Analysed data (in Microsoft Word format). **HOW DATA WILL BE COLLECTED: ** 8-12 participants with a diagnosis of Type II Diabetes Mellitus will be interviewed by the researcher. Individual semi- structured interviews will be conducted. Interviews will be approximately 40 – 60 minutes in length. Due to Covid-19, interviews will be conducted via Microsoft Teams via the UEL Teams Account assigned to the researcher. Interviews will be conducted on Microsoft Teams and will be auto-transcribed. The auto-transcriptions will be reviewed and edited by the researcher. All interviews will be audio recorded (with a Dictaphone) and used to assist transcription by the researcher. Transcription will be created and saved as Word documents (.doc file formats). The transcripts will be organised and analysed by the researcher. Each participant will be given a participant number (in interview chronological order) and all identifiable information (e.g., names, location, identifiable scenarios) anonymised in the transcripts. A separate identifying number will be given to demographic/consent forms. Details of how files can be matched will be stored in a password-protected Excel file. Audio recordings from the encrypted Dictaphone will be uploaded onto the UEL OneDrive for Business prior to transcription, immediately after the interview has ended. Recordings will then be deleted from the device. Audio files will be saved in the UEL OneDrive for Business titled: 'Participant number, Date of interview'. Digital consent forms will be stored in UEL OneDrive for Business with a different participant identifier to audio files/transcripts.	
3.9	**Will you be engaging in deception?**	**YES** ☐	**NO** ☒
	If yes, what will participants be told about the nature of the research, and	If you selected yes, please provide more information here	

	how/when will you inform them about its real nature?		
3.10	**Will participants be reimbursed?**	**YES** ☒	**NO** ☐
	If yes, please detail why it is necessary.	In order to support the recruitment process and to show gratitude, a proxy payment in the form of a voucher redeemable via online retailer, Love2Shop, will be offered in recognition of the breadth of utility it provides. Vouchers will be sent digitally. In the event that a participant chooses to withdraw their contribution to the research, the voucher will remain with the participant in recognition of their time and engagement.	
	How much will you offer? Please note - This must be in the form of vouchers, not cash.	A £10 Love2Shop voucher will be offered to each participant following completion of the interview.	
3.11	**Data analysis:**	Thematic Analysis will be used. I will be following Braun and Clarke's six phase framework for performing a thematic analysis. These steps will include: Step 1: becoming familiar with the data. Step 2: generating initial codes (with supervisor review). Step 3: searching for themes. Step 4: reviewing themes (with supervisor review). Step 5: definition of themes, Step 6: write-up analysis.	

Section 4 – Confidentiality, Security and Data Retention

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations.

If a Research Data Management Plan (RDMP) has been completed and reviewed, information from this document can be inserted here.

4.1	**Will the participants be anonymised at source?**	**YES** ☐	**NO** ☒
	If yes, please provide details of how the data will be anonymised.	Please detail how data will be anonymised	
4.2	**Are participants' responses anonymised or are an anonymised sample?**	**YES** ☒	**NO** ☐
	If yes, please provide details of how data will be anonymised (e.g., all identifying information will be	Each participant will be given a participant number (in interview chronological order) and all identifiable information (e.g., names, location, identifiable scenarios) anonymised in the transcripts. A separate identifying number will be given to demographic/consent forms.	

	removed during transcription, pseudonyms used, etc.).	Details of how files can be matched will be stored in a password-protected Excel file. Transcripts will be reviewed to highlight and remove and direct identifiers and redact any indirect identifiers including a process of pseudonymisation of the data.
4.3	**How will you ensure participant details will be kept confidential?**	There will be a written confidentiality agreement made with participants as part of the consent form. Demographic data will be de-identified and stored separately to any potentially identifiable information. There will be no direct identifiers (e.g., names, postcode) or collected within the demographic questionnaire that could identify participants. Completed demographic questionnaires will be password protected on receipt and deleted from any email servers once uploaded to the secure UEL One Drive for Business.
4.4	**How will data be securely stored and backed up during the research?** Please include details of how you will manage access, sharing and security	Only the researcher, supervisor and examiners will have access to pseudonymised transcripts. Pseudonymised transcripts will be shared with the research supervisor via UEL OneDrive for Business. File names will be participant numbers e.g., P1. The Dictaphone will be stored securely in a lockbox in the researcher's personal office. Data are encrypted and stored on UEL managed storage (UEL OneDrive for Business) The researcher's laptop, from which interviews will be conducted, will be password protected and is equipped to be permanently locked (remotely) in the event of theft or loss. Contact details and other identifiable information will be stored in a folder separate from the audio/video files and transcripts. Hard copies of consent forms will be scanned and electronically stored on the UEL OneDrive for Business. Hard copies will then be shredded.
4.5	**Who will have access to the data and in what form?** (e.g., raw data, anonymised data)	Only the researcher will have access to the raw data. Anonymised transcripts will be shared with the research supervisor via secure UEL email. File names will be participant numbers e.g., P1. Short extracts of transcripts will be provided in the final write-up of the research and any subsequent publications. The final write-up will be uploaded onto UEL repository. Identifiable information will not be included in these extracts. Anonymised transcripts will not be deposited via the UEL repository due to issues with confidentiality and seeking further consent. Only researcher and supervisor will have access to data (i.e., no one outside the research team will be able to access the data). Only anonymised extracts of qualitative feedback data will be presented in the thesis

		and resulting papers, presentations etc. In order to ensure participant confidentiality, only anonymised transcripts will be shared with examiners on request.	
4.6	**Which data are of long-term value and will be retained?** (e.g., anonymised interview transcripts, anonymised databases)	Electronic copies of consent forms will be kept until the thesis has been examined and passed. They will then be erased from the secure server. Audio and video files will be deleted as soon as they have been transcribed. Anonymised transcripts will be kept for three years on UEL's OneDrive for business by the research supervisor, after which point they will be deleted. These are kept securely within UEL servers but may be needed for further publication following the thesis examination.	
4.7	**What is the long-term retention plan for this data?**	Anonymised transcripts will be kept for three years on UEL's OneDrive for business by the research supervisor, after which point they will be deleted. These are kept securely within UEL servers but may be needed for further publication following the thesis examination.	
4.8	**Will anonymised data be made available for use in future research by other researchers?**	**YES** ☐	**NO** ☒
	If yes, have participants been informed of this?	**YES** ☐	**NO** ☐
4.9	**Will personal contact details be retained to contact participants in the future for other research studies?**	**YES** ☐	**NO** ☒
	If yes, have participants been informed of this?	**YES** ☐	**NO** ☐

Section 5 – Risk Assessment

If you have serious concerns about the safety of a participant, or others, during the course of your research please speak with your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g., a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.

5.1	**Are there any potential physical or psychological risks to participants related to taking part?** (e.g., potential adverse effects, pain, discomfort, emotional distress, intrusion, etc.)	**YES** ☒	**NO** ☐

	If yes, what are these, and how will they be minimised?	In recognition of the individual experiences of living through the COVID-19 pandemic and the associated impact in various aspects of our lives, revisiting and recounting these experiences may be emotionally challenging and will require sensitivity and awareness. Additionally, when considering the intersection of physical health conditions with the pandemic and experiences of diagnosis and living with long-term conditions, unresolved and potentially unprocessed emotions may arise. With this in mind, any difficult emotions occurring during the interview will be managed in the same way the researcher would manage the same in clinical work, with the acknowledgment that the researcher role is not of a therapist. The supervisor will always be aware of where and when interviews are occurring. All participants will be signposted to relevant support services post interview and information regarding services available will be documented in the debrief letter. Additionally, participants will be able to stop at any point during the interview process, to take breaks and to withdraw entirely from the process.		
5.2	**Are there any potential physical or psychological risks to you as a researcher?**	**YES** ☒	**NO** ☐	
	If yes, what are these, and how will they be minimised?	In exploring the experiences of those who have lived through the pandemic (as, of course, have I as researcher) there is the potential for vicarious distress as a consequence of being privy to participant's stories and experiences. This will be managed by bringing these issues to supervision with my research supervisor and using the space to process what may feel difficult.		
5.3	**If you answered yes to either 5.1 and/or 5.2, you will need to complete and include a General Risk Assessment (GRA) form (signed by your supervisor). Please confirm that you have attached a GRA form as an appendix:**	**YES** ☒		
5.4	**If necessary, have appropriate support services been identified in material provided to participants?**	**YES** ☒	**NO** ☐	**N/A** ☐

5.5	**Does the research take place outside the UEL campus?**	**YES** ☒	**NO** ☐
	If yes, where?	Online via researcher's private and restricted office space using a laptop computer and MS Teams. Participants will be advised to identify a quiet and private space where they feel able to speak without interruption or fear of being overheard. If the participant is unable to identify suitable conditions for an online interview, alternative means of communication will be sought (i.e., telephone) allowing greater flexibility in terms of finding an appropriate space.	
5.6	**Does the research take place outside the UK?**	**YES** ☐	**NO** ☒
	If yes, where?	Please state the country and other relevant details	
	If yes, in addition to the General Risk Assessment form, a Country-Specific Risk Assessment form must also be completed and included (available in the Ethics folder in the Psychology Noticeboard). Please confirm a Country-Specific Risk Assessment form has been attached as an appendix. Please note - A Country-Specific Risk Assessment form is not needed if the research is online only (e.g., Qualtrics survey), regardless of the location of the researcher or the participants.	**YES** ☐	
5.7	**Additional guidance:** ▪ For assistance in completing the risk assessment, please use the AIG Travel Guard website to ascertain risk levels. Click on 'sign in' and then 'register here' using policy # 0015865161. Please also consult the Foreign Office travel advice website for further guidance. ▪ For on campus students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Director of Impact and Innovation, Professor Ian Tucker (who may escalate it up to the Vice Chancellor). ▪ For distance learning students conducting research abroad in the country where they currently reside, a risk assessment must also be carried out. To minimise risk, it is recommended that such students only conduct data collection online. If the project is deemed low risk, then it is not necessary for the risk assessment to be		

	signed by the Director of Impact and Innovation. However, if not deemed low risk, it must be signed by the Director of Impact and Innovation (or potentially the Vice Chancellor). ▪ Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.

	Section 6 – Disclosure and Barring Service (DBS) Clearance		
6.1	**Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)?** If yes, you will require Disclosure Barring Service (DBS) or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project	**YES** ☐	**NO** ☒
	* You are required to have DBS or equivalent clearance if your participant group involves: (1) Children and young people who are 16 years of age or under, or (2) ‘Vulnerable’ people aged 16 and over with particular psychiatric diagnoses, cognitive difficulties, receiving domestic care, in nursing homes, in palliative care, living in institutions or sheltered accommodation, or involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak with your supervisor.		
6.2	**Do you have DBS or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project?**	**YES** ☐	**NO** ☐
6.3	**Is your DBS or equivalent (for those residing in countries outside of the UK) clearance valid for the duration of the research project?**	**YES** ☐	**NO** ☐
6.4	**If you have current DBS clearance, please provide your DBS certificate number:**	Please enter your DBS certificate number	
	If residing outside of the UK, please detail the type of clearance and/or provide certificate number.	Please provide details of the type of clearance, including any identification information such as a certificate number	

6.5	**Additional guidance:** ▪ If participants are aged 16 or under, you will need two separate information sheets, consent forms, and debrief forms (one for the participant, and one for their parent/guardian). ▪ For younger participants, their information sheets, consent form, and debrief form need to be written in age-appropriate language.

	Section 7 – Other Permissions		
7.1	**Does the research involve other organisations (e.g., a school, charity, workplace, local authority, care home, etc.)?**	**YES** ☐	**NO** ☒
	If yes, please provide their details.	Please provide details of organisation	
	If yes, written permission is needed from such organisations (i.e., if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation). Please confirm that you have attached written permission as an appendix.	**YES** ☐	
7.2	**Additional guidance:** ▪ Before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application or approval letter. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as 'my' or 'I' with 'our organisation' or with the title of the organisation. ▪ If the organisation has their own ethics committee and review process, a SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s.		

	Section 8 – Declarations	
8.1	**Declaration by student. I confirm that I have discussed the ethics**	**YES** ☒

	and feasibility of this research proposal with my supervisor:	
8.2	**Student's name:** (Typed name acts as a signature)	**L M Wood**
8.3	**Student's number:**	**Uxxxxxx**
8.4	**Date:**	**26/04/2022**
Supervisor's declaration of support is given upon their electronic submission of the application		

7.5. Appendix E: Evidence of Ethical Apporval

University of
East London

School of Psychology Ethics Committee

NOTICE OF ETHICS REVIEW DECISION LETTER

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

Reviewer: Please complete sections in blue | **Student:** Please complete/read sections in orange

Details

Reviewer:	**John Turner**
Supervisor:	**Trishna Patel**
Student:	**L M Wood**
Course:	**Prof Doc in Clinical Psychology**
Title of proposed study:	Diabetic patient experiences of shame after acquiring COVID-19.

Checklist

(Optional)

	YES	NO	N/A
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)	☐	☐	☐
Detailed account of participants, including inclusion and exclusion criteria	☐	☐	☐
Concerns regarding participants/target sample	☐	☐	☐
Detailed account of recruitment strategy	☐	☐	☐
Concerns regarding recruitment strategy	☐	☐	☐
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	☐	☐	☐
Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	☐	☐	☐

Clear and detailed outline of data collection	☐	☐	☐
Data collection appropriate for target sample	☐	☐	☐
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point	☐	☐	☐
If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	☐	☐	☐
Concerns regarding data storage (e.g., location, type of data, etc.)	☐	☐	☐
Concerns regarding data sharing (e.g., who will have access and how)	☐	☐	☐
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)	☐	☐	☐
If required, General Risk Assessment form attached	☐	☐	☐
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
If required, Country-Specific Risk Assessment form attached	☐	☐	☐
If required, a DBS or equivalent certificate number/information provided	☐	☐	☐
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	☐	☐	☐
All relevant information included in the participant information sheet (PIS)	☐	☐	☐
Information in the PIS is study specific	☐	☐	☐
Language used in the PIS is appropriate for the target audience	☐	☐	☐
All issues specific to the study are covered in the consent form	☐	☐	☐
Language used in the consent form is appropriate for the target audience	☐	☐	☐
All necessary information included in the participant debrief sheet	☐	☐	☐
Language used in the debrief sheet is appropriate for the target audience	☐	☐	☐
Study advertisement included	☐	☐	☐
Content of study advertisement is appropriate (e.g., researcher's personal contact details are not shared, appropriate language/visual material used, etc.)	☐	☐	☐

Decision options

APPROVED	Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice), to the date it is submitted for assessment.
APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED <u>BEFORE</u> THE RESEARCH COMMENCES	In this circumstance, the student must confirm with their supervisor that all minor amendments have been made **<u>before</u>** the research commences. Students are to do this by filling in the confirmation box at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student's confirmation to the School for its records.

	Minor amendments guidance: typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.
NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED	In this circumstance, a revised ethics application **must** be submitted and approved **before** any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application. **Major amendments guidance:** typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate's ability to ethically, safely and sensitively execute the study.

Decision on the above-named proposed research study

Please indicate the decision:	**APPROVED**

Minor amendments

Please clearly detail the amendments the student is required to make

Major amendments

Please clearly detail the amendments the student is required to make

Assessment of risk to researcher

Has an adequate risk assessment been offered in the application form?	**YES** ☒	**NO** ☐
	If no, please request resubmission with an **adequate risk assessment.**	
If the proposed research could expose the researcher to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:		
HIGH	Please **do not approve a high-risk** application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.	☐
MEDIUM	Approve but include appropriate recommendations in the below box.	☐
LOW	Approve and if necessary, include any recommendations in the below box.	☒
Reviewer recommendations in relation to risk (if any):	Please insert any recommendations	

Reviewer's signature

Reviewer: (Typed name to act as signature)	**John Turner**
Date:	**09/05/2022**

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Ethics Committee

RESEARCHER PLEASE NOTE

For the researcher and participants involved in the above-named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

Confirmation of minor amendments

(Student to complete)

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data

Student name: (Typed name to act as signature)	Please type your full name
Student number:	Please type your student number
Date:	Click or tap to enter a date

Please submit a copy of this decision letter to your supervisor with this box completed if minor amendments to your ethics application are required

7.6. Appendix F :Amendment to Ethical Approval

University of
East London

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of School Ethics Committee).

How to complete and submit the request	
1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents	
A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** ☒
Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒

A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	L M Wood
Programme of study:	Professional Doctorate in Clinical Psychology
Title of research:	Diabetic patient experiences of shame after acquiring COVID-19.
Name of supervisor:	Dr. Trishna Patel

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	**Rationale**
Update to Participant Information Sheet to include enhanced information relating to gift voucher process.	The School of Psychology has replaced Love2Shop gift vouchers with Amazon Vouchers. Furthermore, the process of securing a voucher for participants requires a range of personal details including the participant's name, Date of Birth, home address and National Insurance Number. This information is not currently on the PIS submitted.
Proposed amendment	Rationale for proposed amendment
Proposed amendment	Rationale for proposed amendment
Proposed amendment	Rationale for proposed amendment

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student's signature

Student: (Typed name to act as signature)	**L M Wood**
Date:	**31/05/2022**

Reviewer's decision		
Amendment(s) approved:	**YES** ☒	**NO** ☐
Comments:	1. Please change new wording from 'would' to 'will': 'Participants would be required to submit' and 'This personal information would be stored separately'. 2. Please ensure that reference to 'Love2Shop vouchers' has been replaced in all study materials (e.g., study ad).	
Reviewer: (Typed name to act as signature)	**Trishna Patel**	
Date:	**25/07/2022**	

7.7. Appendix G : Change of Title Approval

University of
East London

School of Psychology Ethics Committee

REQUEST FOR TITLE CHANGE TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for a proposed title change to an ethics application that has been approved by the School of Psychology

By applying for a change of title request, you confirm that in doing so, the process by which you have collected your data/conducted your research has not changed or deviated from your original ethics approval. If either of these have changed, then you are required to complete an 'Ethics Application Amendment Form'.

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	Using your UEL email address, email the completed request form along with associated documents to Dr Jérémy Lemoine (School Ethics Committee Member): j.lemoine@uel.ac.uk
4	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.

Required documents

A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**L M Wood**
Programme of study:	**Professional Doctorate in Clinical Psychology**
Title of research:	**Diabetic patient experiences of shame after acquiring COVID-19.**

Name of supervisor:	**Dr. Trishna Patel**

Proposed title change

Briefly outline the nature of your proposed title change in the boxes below

Old title:	**Diabetic patient experiences of shame after acquiring COVID-19.**
New title:	**Diabetic patient experiences of public and government messaging and help-seeking during the COVID-19 Pandemic**
Rationale:	**In order to more articulately capture the aspirations of the research focus by pulling the lens back on the title page.**

Confirmation

Is your supervisor aware of your proposed change of title and in agreement with it?	**YES** ☒	**NO** ☐
Does your change of title impact the process of how you collected your data/conducted your research?	**YES** ☐	**NO** ☒

Student's signature

Student: (Typed name to act as signature)	**L M Wood**
Date:	**28/02/2023**

Reviewer's decision

Title change approved:	**YES** ☒	**NO** ☐
Comments:	The new title reflects better the research study and will not impact the process of how the data are collected or how the research is conducted.	
Reviewer: (Typed name to act as signature)	**Dr Jérémy Lemoine**	
Date:	**01/03/2023**	

7.8. Appendix H : Amended Participant Information Sheet

Date: 31/05/2022
Version 3.0

University of East London

PARTICIPANT INFORMATION SHEET

Exploring the experiences of diabetic patients during the COVID-19 Pandemic

Contact person: L M Wood, Researcher, Professional Doctorate in Clinical Psychology
Email: uxxxxxx@uel.ac.uk

You are being invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about the study (e.g. friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on the above email.

Who am I?

My name is L M Wood. I am a postgraduate student in the School of Psychology at the University of East London (UEL) and am studying for a Professional Doctorate in Clinical Psychology. As part of my studies, I am conducting the research that you are being invited to participate in.

What is the purpose of the research?

Whilst there has been research into the impact of the pandemic on those who had previously experienced mental health difficulties there is – to date – only limited research on the experiences of those individuals with pre-existing physical health conditions and the emotional impact of living through the pandemic. I would like to find out how people with pre-existing health conditions describe their experiences of seeking help post-COVID. I am also interested to understand what the impact and response to messaging around those with pre-existing health conditions and COVID-19 including government messaging, media and social media.

The research findings that may be of use when considering public health messaging alongside design around post-COVID mental health services in understanding barriers to access for those with pre-existing health difficulties.

Why have I been invited to take part?

To address the study aims, I am inviting people aged 18 and above, who are able to read and communicate in English without the use of an interpreter, to take part in my research. If you have received a diagnosis of type II diabetes and tested positive for COVID-19 since the start of the pandemic, you are eligible to take part in the study.

It is entirely up to you whether you take part or not and participation is voluntary.

What will I be asked to do if I agree to take part?

If you would like to participate, I will invite you to attend an interview online using Microsoft Teams (an online platform) lasting about an hour, where I will ask you questions about your experiences of living with diabetes type II during the COVID-19 pandemic. The interviews will hopefully feel very much like an informal chat and you can take breaks during the interview and can choose at any time during the interview to stop and/or withdraw your consent to participate. You do not need to provide a reason for doing so. Our conversation will be audio recorded for research purposes.

All participants will be offered a £10 Amazon voucher for offering their time and will be sent, via email, following completion of the research interview. Participants would be required to submit their full name, date of birth, home address and National Insurance Number in order to process the voucher through the University of East London. This personal information would be stored separately to interview data. The voucher is voluntary and is not a requirement of participation.

Can I change my mind?

You can change your mind without giving a reason at any point until the interviews have been analysed. Analysis will begin two weeks after our interviews. If you would like to withdraw your information completely from the research, please contact the researcher before this using the contact details at the top of this document.

Are there any disadvantages to taking part?

Taking part in these interviews may remind you of experiences that you have found difficult. You have the right not to answer questions that you do not wish to and will have the opportunity to discuss any difficult feelings that emerge at the end of the interview. You will also be provided with a list of supporting agencies should you feel that you would like to talk to someone after the interview is completed.

How will the information I provide be kept secure and confidential?
Your privacy and safety will be respected at all times. All the information discussed in the interview will be kept confidential, unless I am concerned that you, or someone else, is at risk of harm. In this case I would need to speak to someone else as it is my duty of care to keep you, and others, safe from harm. If I felt this was necessary, I would always try to discuss this with you first.

All interviews will be audio-recorded. The researcher will write-up the audio recordings and anonymise identifiable information in the form of transcripts. All data will be stored on a password protected Microsoft OneDrive (only accessible to the research team) hosted on the secure UEL Server. The written information will be anonymous, and for the purpose of the study the information you have provided will be under a false name. Short extracts of the interviews may be used in the research study report. The researcher's supervisor and examiners may read anonymised full transcripts.

What will happen to the results of the research?
The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository Registry of Open Access Repositories (ROAR). Findings will also be disseminated to a range of audiences (e.g., academics, clinicians, public, etc.) through journal articles, conference presentations, talks, magazine articles, blogs. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally with identifying information removed and replaced with anonymous numerical identifiers.

Names, contact details, and anonymised reports of the interviews will be held electronically on a password protected device for three years after the study completion date (estimated May 2023).

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection

Who has reviewed the research?

My research has been approved by the School of Psychology Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Who can I contact if I have any questions/concerns?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

L M Wood
Email: uxxxxxx@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor (and Chair of the School Ethics Committee) Dr. Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: t.patel@uel.ac.uk

Thank you for taking the time to read this information sheet

7.9. Appendix I : Participant Consent Form

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Exploring the experiences of diabetic patients during the COVID-19 Pandemic

Contact person: L M Wood
Email: uxxxxxxx@uel.ac.uk

	Please initial
I confirm that I have read the participant information sheet dated 06/01/2022 (version 1.0) for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in the study is voluntary and that I may withdraw at any time, without explanation or disadvantage.	
I understand that if I withdraw during the study, my data will not be used.	
I understand that I have two weeks from the date of the interview to withdraw my data from the study.	
I understand that the interview will be recorded using a secure Dictaphone recording device alongside audio transcription software on Microsoft Teams	
I understand that my personal information and data, including audio recordings from the research will be securely stored and remain confidential. Only the research team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from my interview/group level data may be used in material such as conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify me.	

I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to.	
I agree to take part in the above study.	

Participant’s Name (BLOCK CAPITALS)

………

Participant’s Signature

………

Researcher’s Name (BLOCK CAPITALS)

………

Researcher’s Signature

………

Date

………

7.10. Appendix J : Data Management Plan

UEL Data Management Plan

Completed plans **must** be sent to researchdata@uel.ac.uk for review

If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

Administrative Data	
PI/Researcher	L M Wood
PI/Researcher ID (e.g. ORCiD)	0000-0002-5441-2444
PI/Researcher email	Uxxxxxxx@uel.ac.uk
Research Title	Diabetic patient experiences of shame after acquiring COVID-19
Project ID	N/A
Research Duration	April 2022 – July 2023
Research Description	Whilst there has been a considerable body of research around the impact of the pandemic on those who had previously experienced mental health difficulties (and extensive research on the relationship between pre-morbid physical health conditions i.e. diabetes, hypertension, obesity) there is – to date – no research on the experiences of those individuals and the emotional impact of living through the pandemic. I would like to find out how do people with premorbid health conditions describe their experiences of help-seeking post-COVID

	and what are the impacts of – and responses to - messaging around premorbid health and COVID-19 i.e government messaging, media and closer social systems. This research may produce findings that may be of use when considering public health messaging alongside design around post-COVID mental health services in understanding barriers to access for those with co-morbid health difficulties.
Funder	N/A – part of a professional doctorate
Grant Reference Number (Post-award)	N/A
Date of first version (of DMP)	10/01/2022
Date of last update (of DMP)	31/01/2022
Related Policies	• BPS Practice Guidelines Third Edition 2017 • NHS England response to the specific equality duties of the Equality Act 2010 • UEL Data Backup Policy • THE NHS CONSTITUTION ENGLAND DATA MANAGEMENT POLICY • UEL Statement on Research Integrity • UEL Statement on Research Ethics • The Data Protection Act • Research Data Management Policy 2019
Does this research follow on from previous research? If so, provide details	N/A
Data Collection	
What data will you collect or create?	Data will be : • Personal data collected on consent forms including name, email address and/or telephone number. • Demographic data including age category, sex, ethnicity, length of diabetes diagnosis, country of residence (England, Wales, Scotland, Northern Island) • Interview transcripts (in Microsoft Word format 8-12 participants)

	- Interview recordings (in .mp3 format – 8-12 participants) - Analysed data (in Microsoft Word format)
How will the data be collected or created?	- 8-12 participants with a diagnosis of Type II Diabetes Mellitus will be interviewed by the researcher. Individual semi- structured interviews will be conducted. Interviews will be approximately 40 – 60 minutes in length. - Due to Covid19, interviews will be conducted via Microsoft Teams via the UEL Teams Account assigned to the researcher. - Interviews will be conducted on Microsoft Teams and will be auto-transcribed. The auto-transcriptions will be reviewed and edited by the researcher. - All interviews will be audio recorded (with a Dictaphone) and used to assist transcription by the researcher. Transcription will be created and saved as Word documents (.doc file formats). The transcripts will be organised and analysed by the researcher. - Each participant will be given a participant number (in interview chronological order) and all identifiable information (e.g. names, location, identifiable scenarios) anonymised in the transcripts. A separate identifying number will be given to demographic/consent forms. Details of how files can be matched will be stored in a password-protected Excel file. - Audio recordings from the encrypted Dictaphone will be uploaded onto the UEL OneDrive for Business prior to transcription, immediately after the interview has ended. Recordings will then be deleted from the device. - Audio files will be saved in the UEL OneDrive for Business titled: 'Participant number, Date of interview'. - Digital consent forms will be stored in UEL OneDrive for Business with a different participant identifier to audio files/transcripts.
Documentation and Metadata	
What documentation and metadata will accompany the data?	- Participant information sheets - List of guide interview questions - Debrief sheet. - Participant recruitment poster/ letter. - PARTICIPANT IDENTIFER FILES (i.e. P194) o Demographic data o Consent forms - PARTICIPANT NUMBER in order of interview (i.e. P1) o .MP3 Audio files o Word.doc transcription files

Ethics and Intellectual Property	
Identify any ethical issues and how these will be managed	• UEL Ethics approval will be sought before recruitment can take place. During recruitment, information sheets will be given to potential participants and given again prior to interviews. • Once identified, selected participants will be provided with an information sheet explaining the research project and provided with opportunities to ask questions. They will also be requested to complete a consent form on MS Teams. The consent form will ask participants to tick a list of statements to ensure that they understand what they are consenting to in terms of participation, data collection, storage and use. • Participants will also be reminded that they are under no obligation to remain in the study if they wish to withdraw and that there are no negative consequences to withdrawing from the study or withdrawing their data from the study following participation before analysis. This date shall be clearly stated on the information sheets. • MS Teams video recordings will not be used because of the potential breaches to anonymity and the large file sizes. Consultation with service users raised issues regarding the video component of recordings. Instead, Teams audio-transcription will be used as it allows for additional anonymity. As MS Teams does not allow for audio only recording, a Dictaphone will be used to record sessions where participants have not opted out in order to support the158ranscripttion process for accuracy. • There will be a written confidentiality agreement made with participants as part of the consent form. • Demographic data will be de-identified using aggregated age ranges (18-24 / 25-34 / 35 – 44 / 45 - 54 / 55- 64 / 65 – 74 / 75 – 84 / 85+)and broad geographic capture (i.e. county). Additionally, there will be no direct identifiers (eg names, postcode) or collected within the demographic questionnaire that could identify participants. • Any distress occurring during the interview will be managed in the same way the researcher would manage distress in clinical work. The supervisor will always be aware of where and when interviews are occurring. All participants will be signposted to relevant support services post interview and information regarding services available will be documented in the debrief letter.

Identify any copyright and Intellectual Property Rights issues and how these will be managed	There are no known copyright of Intellectual Property Issues. As this is a doctoral thesis, there are no copyright or intellectual property rights issues. The data will be owned by the researcher.
Storage and Backup	
How will the data be stored and backed up during the research?	• All data will be stored on UEL OneDrive for Business cloud. • Audio files and transcripts will be stored in separate folders to demographic/consent forms only accessible by the researcher on a UEL OneDrive for business. Contact details and other identifiable information will be stored in a folder separate from the audio files and transcripts. Transcripts and audio files will be labelled with a different participant number to the contact/demographics/consent files and will only be linked through access to a separately held and password protected Excel spreadsheet that will allow files to be associated. • Transcripts will be stored on both the researchers and supervisors secure accounts (so there is a backup)
How will you manage access and security?	• Only the researcher, supervisor and examiners will have access to pseudonymised transcripts. • Pseudonymised transcripts will be shared with the research supervisor via UEL OneDrive for Business. • File names will be participant numbers e.g. P1. • The Dictaphone will be stored securely in a lockbox in the researcher's personal office. • Data are encrypted and stored on UEL managed storage (UEL OneDrive for Business) • The researcher's laptop, from which interviews will be conducted, will be password protected and is equipped to be permanently locked (remotely) in the event of theft or loss.
Data Sharing	
How will you share the data?	• Short extracts of transcripts will be provided in the final write-up of the research and any subsequent publications. The final write-up will be uploaded onto UEL repository. • Identifiable information will not be included in these extracts. Anonymised transcripts will not be deposited via the UEL repository due to issues with confidentiality.

Are any restrictions on data sharing required?	• Only anonymised extracts of qualitative feedback data will be presented in the thesis and resulting papers, presentations etc. In order to ensure participant confidentiality, apart from anonymised transcripts, other data will not be shared with anyone outside of the research team.
Selection and Preservation	
Which data are of long-term value and should be retained, shared, and/or preserved?	Electronic copies of consent forms and files linking the participants with their data will be kept until the thesis has been examined and passed. They will then be erased from the secure server. Audio files will be deleted as soon as they have been transcribed.
What is the long-term preservation plan for the data?	Transcripts will be kept for three years on UEL's OneDrive for business by the research supervisor, after which point they will be deleted. These are kept securely within UEL servers but may be needed for further publication following the thesis examination.
Responsibilities and Resources	
Who will be responsible for data management?	L M Wood (researcher) Supervised by Dr. Trishna Patel
What resources will you require to deliver your plan?	Laptop, audio-recorder, access to UEL's OneDrive for Business.
Review	
	Please send your plan to researchdata@uel.ac.uk **We will review within 5 working days and request further information or amendments as required before signing**

Date: 20220210	Reviewer name: Penny Jackson Assistant Manager (Research Data Management)

Guidance

Brief information to help answer each section is below. Aim to be specific and concise. For assistance in writing your data management plan, or with research data management more generally, please contact: **researchdata@uel.ac.uk**

Administrative Data

Related Policies

List any other relevant funder, institutional, departmental or group policies on data management, data sharing and data security. Some of the information you give in the remainder of the DMP will be determined by the content of other policies. If so, point/link to them here.

Data collection

Describe the data aspects of your research, how you will capture/generate them, the file formats you are using and why. Mention your reasons for choosing particular data standards and approaches. Note the likely volume of data to be created.

Documentation and Metadata

What metadata will be created to describe the data? Consider what other documentation is needed to enable reuse. This may include information on the methodology used to collect the data, analytical and procedural information, definitions of variables, the format and file type of the data and software used to collect and/or process the data. How will this be captured and recorded?

Ethics and Intellectual Property

Detail any ethical and privacy issues, including the consent of participants. Explain the copyright/IPR and whether there are any data licensing issues – either for data you are reusing, or your data which you will make available to others.

Storage and Backup

Give a rough idea of data volume. Say where and on what media you will store data, and how they will be backed-up. Mention security measures to protect data which are sensitive or valuable. Who will have access to the data during the project and how will this be controlled?

Data Sharing

Note who would be interested in your data, and describe how you will make them available (with any restrictions). Detail any reasons not to share, as well as embargo periods or if you want time to exploit your data for publishing.

Selection and Preservation

Consider what data are worth selecting for long-term access and preservation. Say where you intend to deposit the data, such as in UEL's data repository (https://repository.uel.ac.uk) or a subject repository. How long should data be retained?

7.11. Appendix K: Participant Debrief Sheet

University of East London

PARTICIPANT DEBRIEF SHEET

Diabetic patient experiences of public and government messaging and help-seeking during the COVID-19 pandemic

Thank you for participating in my research study on diabetic patient experiences during the COVID-19 pandemic. This document offers information that may be relevant in light of you having now taken part.

How will my data be managed?

The University of East London is the Data Controller for the personal information processed as part of this research project. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. More detailed information is available in the Participant Information Sheet, which you received when you agreed to take part in the research.

What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository, the Registry of Open Access Repositories ROAR. Findings will also be disseminated to a range of audiences (e.g., academics, clinicians, public, etc.) through journal articles, conference presentations, talks, magazine articles, and blogs. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally with personally identifying information being removed and replaced with a numerical identifier.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised research data will be securely stored by Dr. Trishna Patel for a maximum of 3 years, following which all data will be deleted.

What if I been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise distress or harm of any kind. Nevertheless, it is possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways, you may find the following resources/services helpful in relation to obtaining information and support:

Diabetes UK
https://www.diabetes.org.uk/
0345 123 2399

Diabetes UK has active online and in-person support groups working locally all over the United Kingdom. In addition, they host an online forum for posting questions and learning about the experiences of others living with diabetes.

Support groups typically meet once a month, but there are additional opportunities to take part in many other activities such as fundraising, campaigning and raising awareness.

In addition, the website has a dedicated section on diabetes and COVID-19 and can be found by clicking on this link : https://www.diabetes.org.uk/about_us/news/coronavirus

Diabetes UK Advocacy Service
Tel: 020 7424 1847
provides support and information for vulnerable people with diabetes, including writing letters and making calls on behalf of clients.

Long COVID Support Network
https://www.longcovid.org
Long Covid Support was formed by a group of people struggling to recover from Covid-19, who found each other online and have been facilitating international peer support and campaigning in the UK for recognition, rehabilitation and research into treatments since May 2020.

Your COVID Recovery
https://www.yourcovidrecovery.nhs.uk
NHS decicated website to help those who are experiencing the aftereffects of COVID-19 to understand what has happened and what to expect as part of the recovery process. There is a dedicated page to support those living with Diabetes that focuses on medication, future hospital appointments and ongoing symptoms to be aware of.

NHS Direct
Tel : 111
24-hour nurse-led health telephone service.

Equality and Human Rights Commission Helpline
www.equalityhumanrights.com
England – tel: 0845 604 6610 or text: 0845 604 6620
Scotland – tel: 0845 604 5510 or text: 0845 604 5520
Wales – tel: 0845 604 8810 or text 0845 604 8820

Who can I contact if I have any questions/concerns?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

L M Wood, University of East London, uxxxxxx@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Dr. Trishna Patel. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: t.patel@uel.ac.uk

Or, in their capacity as Chair of the School Ethics Committee:

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

Thank you for taking part in my study

7.12. Appendix L : Recruitment Plan and Materials

Email Correspondence

The emails below were sent to relevant diabetes-focused organisations that may have been in a position to distribute the research advertisement via online forums and mailing lists. Specific details of organisations approached have not been included in order to protect the anonymity of participants.

Initial Email To Forum Moderators

To whom it may concern,

Re Research Advert for Professional Doctorate in Clinical Psychology Thesis
Experience of people living with Type II diabetes during the COVID-19 pandemic

I would be grateful if you would please accept the attached letter of approval from The University of East London Ethics Committee providing clearance to undertake research looking into the experience of those living with type II diabetes during the pandemic.

I would only post the research advert once (and take your advice on the most appropriate forum to post into) and will not contact forum members directly at any time.

Many thanks for letting me know whether you are happy for me to join your forum and post the research advert attached.

Best wishes,
L M Wood

—
LM Wood
Trainee Clinical Psychologist (2020 Entry)
School of Psychology
The University of East London

Initial Letter To Relevant Organisations re Distribution of Printed Materials

To whom it may concern,

Re Research Advert for Professional Doctorate in Clinical Psychology Thesis
Experience of people living with Type II diabetes during the COVID-19 pandemic

Following my telephone conversation with your helpful colleague this morning, I am writing – as per their suggestion – to ask whether you may be able to help with a piece of research I have undertaken exploring the experiences of people living with

Type 2 diabetes during the COVID-19 pandemic. This is as part of my training as a Clinical Psychologist at the University of East London.

My research aims to explore the ways in with government and public health messaging, during the COVID-19 pandemic, may have been experienced by people living with Type 2 diabetes and how this may have impacted upon help-seeking. The research study is supervised by Dr. Trishna Patel (Deputy Research Director and Chair of the School of Psychology Research Ethics Committee at the University of East London) and it has ethical approval from the university.

I would like to speak with any people living with Type 2 diabetes who have been living in the UK since March 2020 and have included, with this letter, a copy of my research advertisement to give you further details on how potential research participants may contact me and a little more information about the study.

As I am particularly keen to be able to let potential research participants, who may not have access to the internet and social media/email platforms, know about the study, your colleague mentioned to me that it may be possible to distribute printed copies of the research adverts and some fliers as in-person support groups may be restarting over the coming months. With this in mind, I have enclosed some printed materials and will very happily supply more should there be the demand.

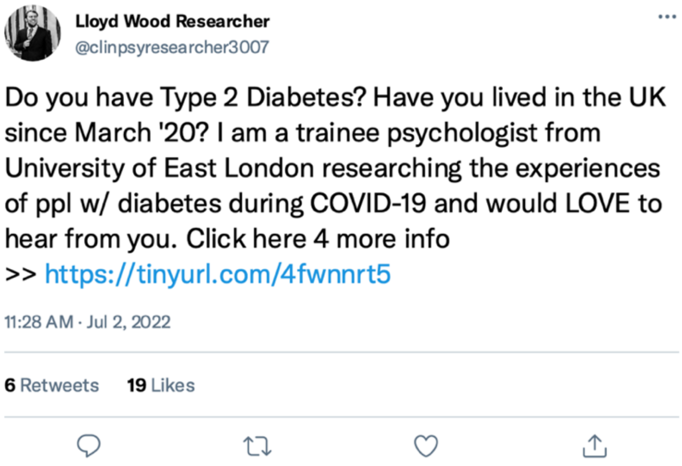
Please do not hesitate to get back in touch with me should you have any questions or if it would be helpful to share more information with you about the study either during the recruitment phase or on completion of the research by way of sharing my findings with you.

Best wishes,

—
L M Wood
Trainee Clinical Psychologist (2020 Entry)
School of Psychology
The University of East London

Social Media

A twitter account and a specific Facebook account were both set up to be able to communicate with moderators of peer-to-peer online support groups, including those affiliated to third sector organisations as well as those established and moderated by individuals living with diabetes.



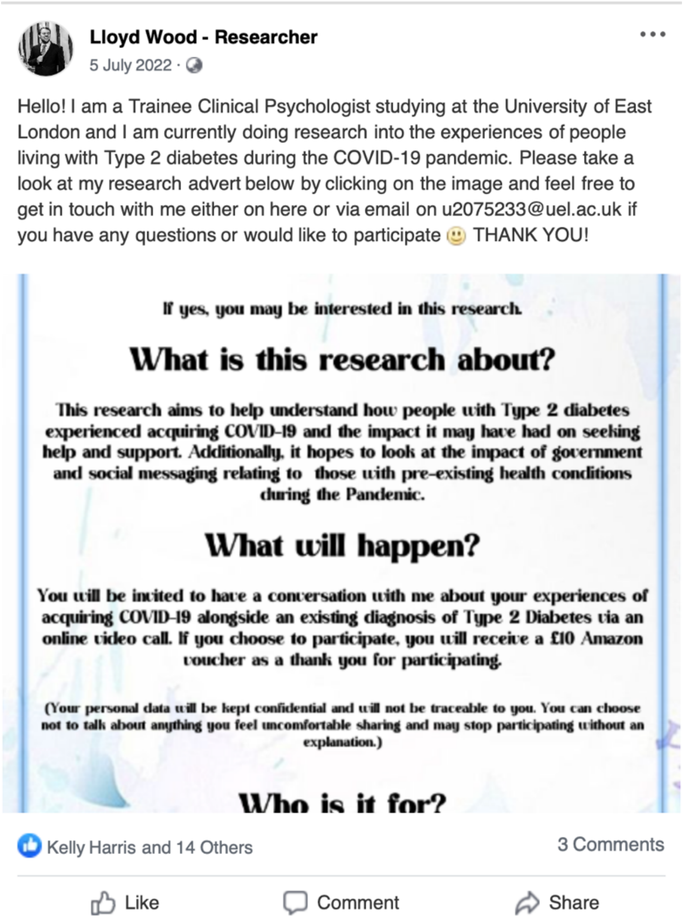
Lloyd Wood Researcher
@clinpsyresearcher3007

Do you have Type 2 Diabetes? Have you lived in the UK since March '20? I am a trainee psychologist from University of East London researching the experiences of ppl w/ diabetes during COVID-19 and would LOVE to hear from you. Click here 4 more info
>> https://tinyurl.com/4fwnnrt5

11:28 AM · Jul 2, 2022

6 Retweets **19** Likes

Twitter Research Advertisement (July 2022)



Lloyd Wood - Researcher
5 July 2022 ·

Hello! I am a Trainee Clinical Psychologist studying at the University of East London and I am currently doing research into the experiences of people living with Type 2 diabetes during the COVID-19 pandemic. Please take a look at my research advert below by clicking on the image and feel free to get in touch with me either on here or via email on u2075233@uel.ac.uk if you have any questions or would like to participate 🙂 THANK YOU!

If yes, you may be interested in this research.

What is this research about?

This research aims to help understand how people with Type 2 diabetes experienced acquiring COVID-19 and the impact it may have had on seeking help and support. Additionally, it hopes to look at the impact of government and social messaging relating to those with pre-existing health conditions during the Pandemic.

What will happen?

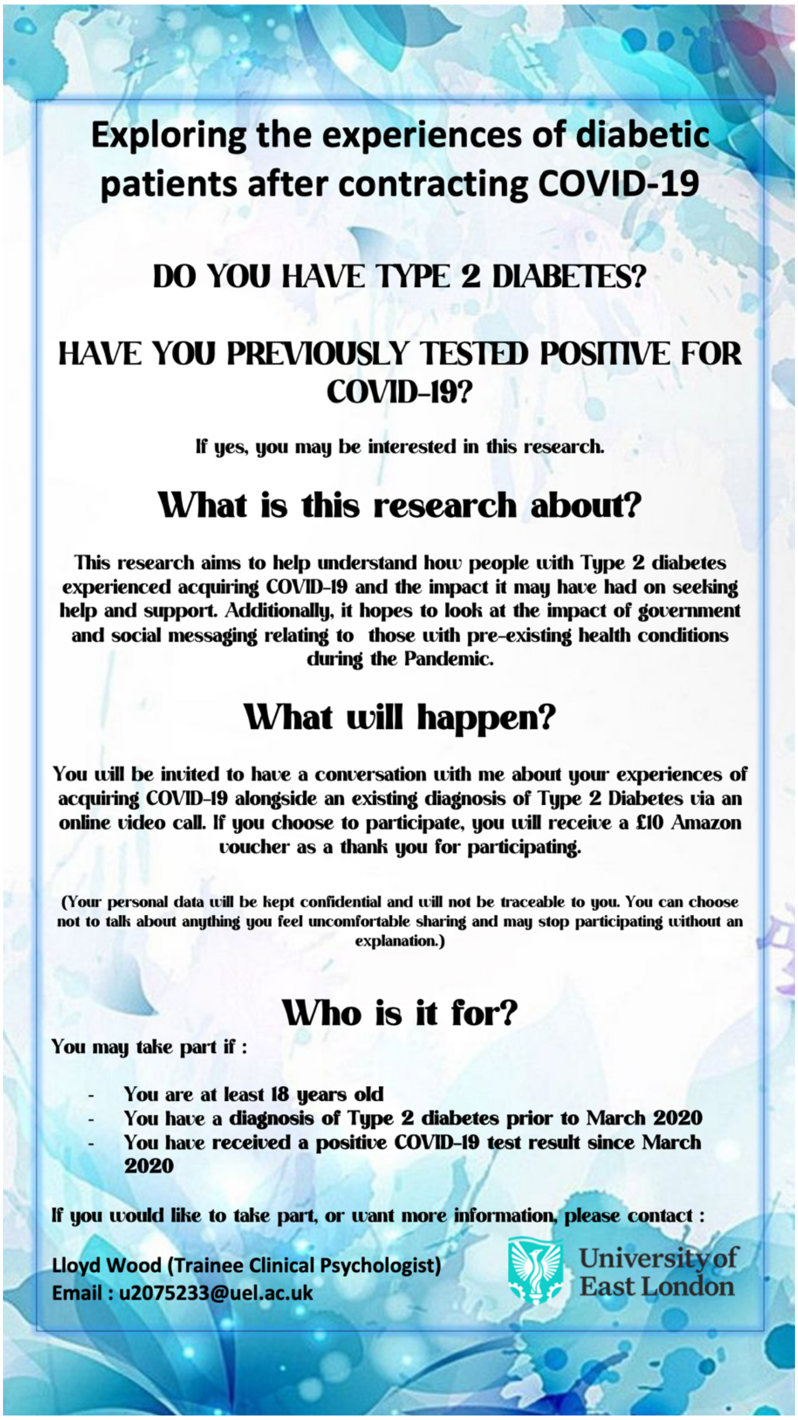
You will be invited to have a conversation with me about your experiences of acquiring COVID-19 alongside an existing diagnosis of Type 2 Diabetes via an online video call. If you choose to participate, you will receive a £10 Amazon voucher as a thank you for participating.

(Your personal data will be kept confidential and will not be traceable to you. You can choose not to talk about anything you feel uncomfortable sharing and may stop participating without an explanation.)

Who is it for?

Kelly Harris and 14 Others 3 Comments

Facebook Research Advertisement (July 2022)



Exploring the experiences of diabetic patients after contracting COVID-19

DO YOU HAVE TYPE 2 DIABETES?

HAVE YOU PREVIOUSLY TESTED POSITIVE FOR COVID-19?

If yes, you may be interested in this research.

What is this research about?

This research aims to help understand how people with Type 2 diabetes experienced acquiring COVID-19 and the impact it may have had on seeking help and support. Additionally, it hopes to look at the impact of government and social messaging relating to those with pre-existing health conditions during the Pandemic.

What will happen?

You will be invited to have a conversation with me about your experiences of acquiring COVID-19 alongside an existing diagnosis of Type 2 Diabetes via an online video call. If you choose to participate, you will receive a £10 Amazon voucher as a thank you for participating.

(Your personal data will be kept confidential and will not be traceable to you. You can choose not to talk about anything you feel uncomfortable sharing and may stop participating without an explanation.)

Who is it for?

You may take part if :

- You are at least 18 years old
- You have a diagnosis of Type 2 diabetes prior to March 2020
- You have received a positive COVID-19 test result since March 2020

If you would like to take part, or want more information, please contact :

Lloyd Wood (Trainee Clinical Psychologist)
Email : u2075233@uel.ac.uk

University of East London

Research Poster for Online Distribution

7.13. Appendix M : Demographic Questionnaire

Gender

How would you describe your gender?

____

Age:	18-24	[ ]
	25-34	[ ]
	35 – 44	[ ]
	45 - 54	[ ]
	55- 64	[ ]
	65 – 74	[ ]
	75 – 84	[ ]
	85+	[ ]

Ethnicity/cultural background

How would you describe your ethnicity and cultural background? (e.g., Black British, Caribbean descent/ Dual heritage, African and Irish descent)

____

Duration of Diabetes Diagnosis

Please share an approximate duration of time (years or months) since you found out about your diabetes

____

7.14. Appendix N : Interview Schedule

Based upon the initial discussions with those experiencing the effects of Long-COVID alongside the existing research literature (and guidance from Ryan et al., 2009) semi-structured interviews will follow a guide for areas to be covered during the interview. How the interview may unfold with be shaped by the individual participant's responses.

Introductions / engagement

- Restate consent
- Restate confidentiality and option to withdraw
- Decide approximate length of interview
- Assess and review technical complications and protocols

Services Accessed

- What type of NHS services have you accessed in the past or are currently accessing?
- What has your experience been of accessing these services (e.g., medication, advice, community services)

History of diagnosis

- Could you tell me how and when you came to learn you had T2DM?
    - What year did you find out?
    - Where were you diagnosed?
- What did you do when you found about having T2DM?
    - Confide in family/friends?
    - Do research?
    - Sought advice? (i.e., wider NHS services, charities or support groups?)
    - Lifestyle changes?
    - Alternative/complimentary treatments?
- What ideas do you have around the causes of your T2DM?
- Could you tell me about your experiences of being diagnosed with T2DM?

T2DM and the Pandemic

- Could you tell me about your experience of living with T2DM during the pandemic?
- Has the pandemic influenced the way you perceive T2DM?
    - If so, in what ways?
- Has the pandemic influenced your T2DM self-management/self-care?
    - If so, in what ways?
- Has the pandemic influenced your relationship with those involved in your care?

- How do you think your diagnosis of T2DM might influence your experiences of day-to-day life, engagement with services, relationships, anything else during the pandemic?

Seeking Help

- Why/What was it (about your experience(s)/symptoms) that meant you have not sought help?
- What happened when you sought help?
- Have you done anything further/received further advice or support?
- Please describe any changes to the way you live with/manage your symptoms of diabetes following your experience of COVID-19.

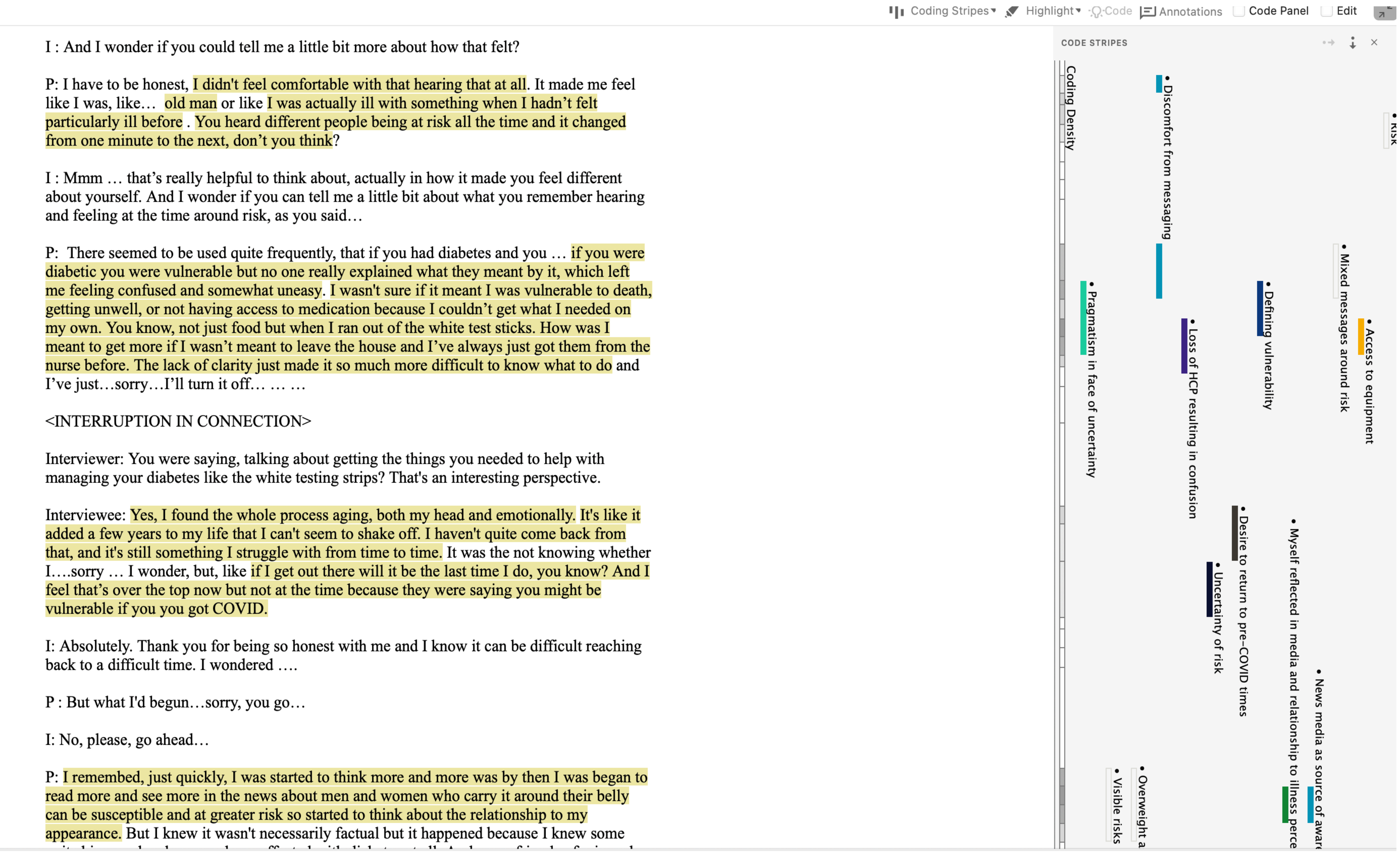
Aide-mémoire for Interviewer (additional prompts)

- What do you mean?
- How does that make you feel?
- Please could you tell me more?
- How do you think about that?
- What was that like for you?
- Please can you give me an example?

Interview Debrief

- How has the conversation we've just had felt for you?
- Is there anything that you found difficult about the interview?
- Is there anything that you would prefer we left out of the transcript?
- Do you have any questions for me at this stage?
- You are able to contact me at any point if you have questions via the contact details in my email to you (including right to withdraw)
- I'd like to run through a couple of organisations should you require any further support after our chat today and will send these details to you in an email immediately following our call.
- Thank you for your time.

7.15. Appendix O : Transcript Example taken from NVivo 13



I : And I wonder if you could tell me a little bit more about how that felt?

P: I have to be honest, I didn't feel comfortable with that hearing that at all. It made me feel like I was, like… old man or like I was actually ill with something when I hadn't felt particularly ill before . You heard different people being at risk all the time and it changed from one minute to the next, don't you think?

I : Mmm … that's really helpful to think about, actually in how it made you feel different about yourself. And I wonder if you can tell me a little bit about what you remember hearing and feeling at the time around risk, as you said…

P: There seemed to be used quite frequently, that if you had diabetes and you … if you were diabetic you were vulnerable but no one really explained what they meant by it, which left me feeling confused and somewhat uneasy. I wasn't sure if it meant I was vulnerable to death, getting unwell, or not having access to medication because I couldn't get what I needed on my own. You know, not just food but when I ran out of the white test sticks. How was I meant to get more if I wasn't meant to leave the house and I've always just got them from the nurse before. The lack of clarity just made it so much more difficult to know what to do and I've just…sorry…I'll turn it off… … …

<INTERRUPTION IN CONNECTION>

Interviewer: You were saying, talking about getting the things you needed to help with managing your diabetes like the white testing strips? That's an interesting perspective.

Interviewee: Yes, I found the whole process aging, both my head and emotionally. It's like it added a few years to my life that I can't seem to shake off. I haven't quite come back from that, and it's still something I struggle with from time to time. It was the not knowing whether I….sorry … I wonder, but, like if I get out there will it be the last time I do, you know? And I feel that's over the top now but not at the time because they were saying you might be vulnerable if you you got COVID.

I: Absolutely. Thank you for being so honest with me and I know it can be difficult reaching back to a difficult time. I wondered ….

P : But what I'd begun…sorry, you go…

I: No, please, go ahead…

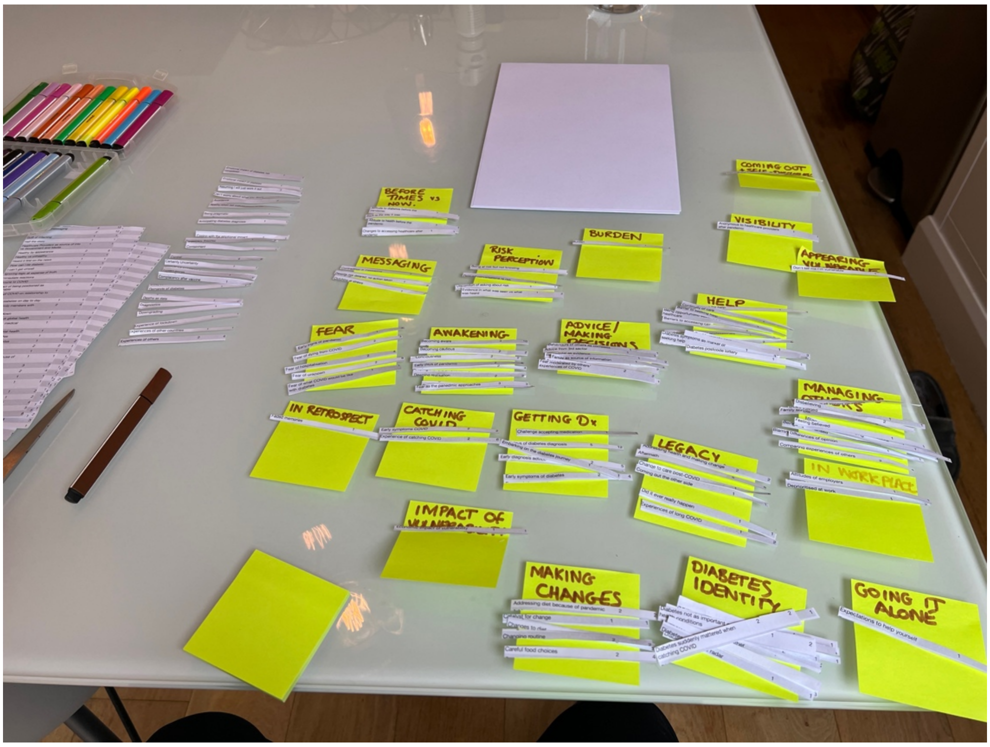
P: I remembed, just quickly, I was started to think more and more was by then I was began to read more and see more in the news about men and women who carry it around their belly can be susceptible and at greater risk so started to think about the relationship to my appearance. But I knew it wasn't necessarily factual but it happened because I knew some

7.16. Appendix P : Initial Codes

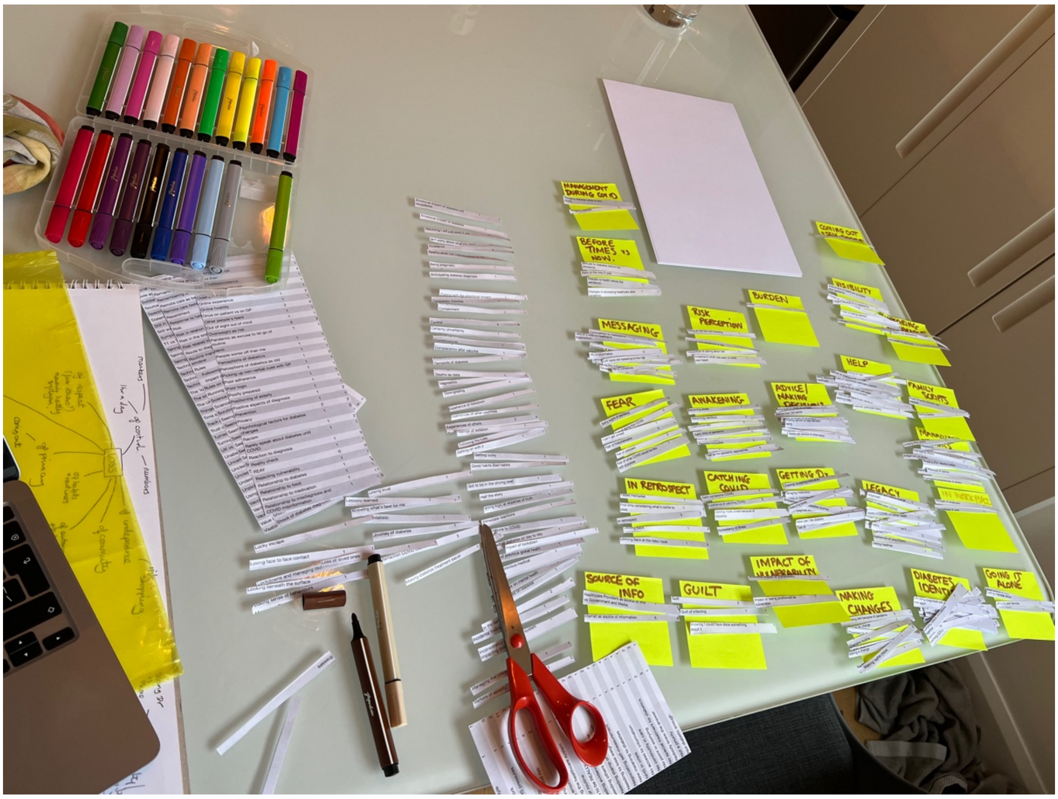
Addressing diet because of pandemic
Addressing health and making change
Adjustment
Advice from 3rd sector
Aftermath of personal decisions
Anger with the system
Anecdotal as evidence
Anecdote vs fact
Anonymous to healthcare providers after pandemic
Anticipating diabetes diagnosis
Apathy when not individualised to me
Appearing weak in seeking help
Assumptions I will just work it out
Attitudes of employers
Avoidance
Awakening to reality of diabetes
Back to the way it was
Barrier to seeking help
Barriers to accessing GP
Becoming cautious
Before the pandemic health
Before times being lost
Behaviours moderated by experiences of others
Behaviours of others as compass
Behind the curve
Being at risk but not knowing why
Being healthy vs being diabetic
Being pushed and pulled in different directions
Being opportunistic seeking help from healthcare
Being pragmatic
Dawning realisation
Deaths as data
Defining Vulnerability
Demands of diabetes on others
Deprioritised at work
Desire to return to pre-covid times
Diabetes a poor lifestyle disease
Diabetes as a lesser priority
Diabetes as who I am
Diabetes falling off the radar
Diabetes felt irrelevant
Diabetes less compared to other illnesses
Diabetes not as important as other health conditions
Diabetes vs old vs unhealthy
Diabetes suddenly mattered when catching COVID
Diabetes symptoms as marker of seeking help
Diabetic all over again
Diabetic or just unhealthy
Did it ever really happen?
Differences of opinion
Disbelieving
Discomfort through messaging
Discriminated because of appearance
Don't tell me I'm vulnerable
Doubly remote care
Downgrading
Early advice
Early signs of pandemic
Early symptoms
Early symptoms COVID

Being Problematised	Early signs that diabetes mattered
Blame	Economic impact of vulnerability
Blaming diabetes (self)	Embarking on the diabetes journey
Burdening the system	Emotional impact of diabetes
Can't worry about what you don't understand	Emotional impact of diabetes not considered
Careful food choices	Evidence in what was seen vs what was heard
Catalyst for change	Expectations to help yourself
Certainty vs Uncertainty	Experience of care
Challenge accepting medication	Experience of catching COVID
Change to care planning	Experience of lockdown
Change to care post-COVID	Experience of two stripes
Changes to accessing healthcare after pandemic	Experiences of long COVID
Changes to health routines	Experiences of other countries
Clutching at straws	Experiences of others
Coming into awareness	Faded memories
Coming out	Family as source of information
Coming out the other side	Family conflict arising
Comparing experiences of others	Famly scripts on 'being unwell'
Complacency after vaccine	Fear as the panedmic approaches
Consciousness	Fear moderated by others' experiences of COVID
Confidence in medical professionals	Fear of dying from COVID
Consequences of avoidance	Fear of hospitalisation
Consideration of impact on others	Fear of what COVID would be like with diabetes
Conspiracy theories	Feeling believed
Containment	Feeling deprioritised
Continuity of care	Feeling like a liability
Contradiction in messaging	Feeling like part of the problem
Coping with the emotional impact	Feelings of isolation

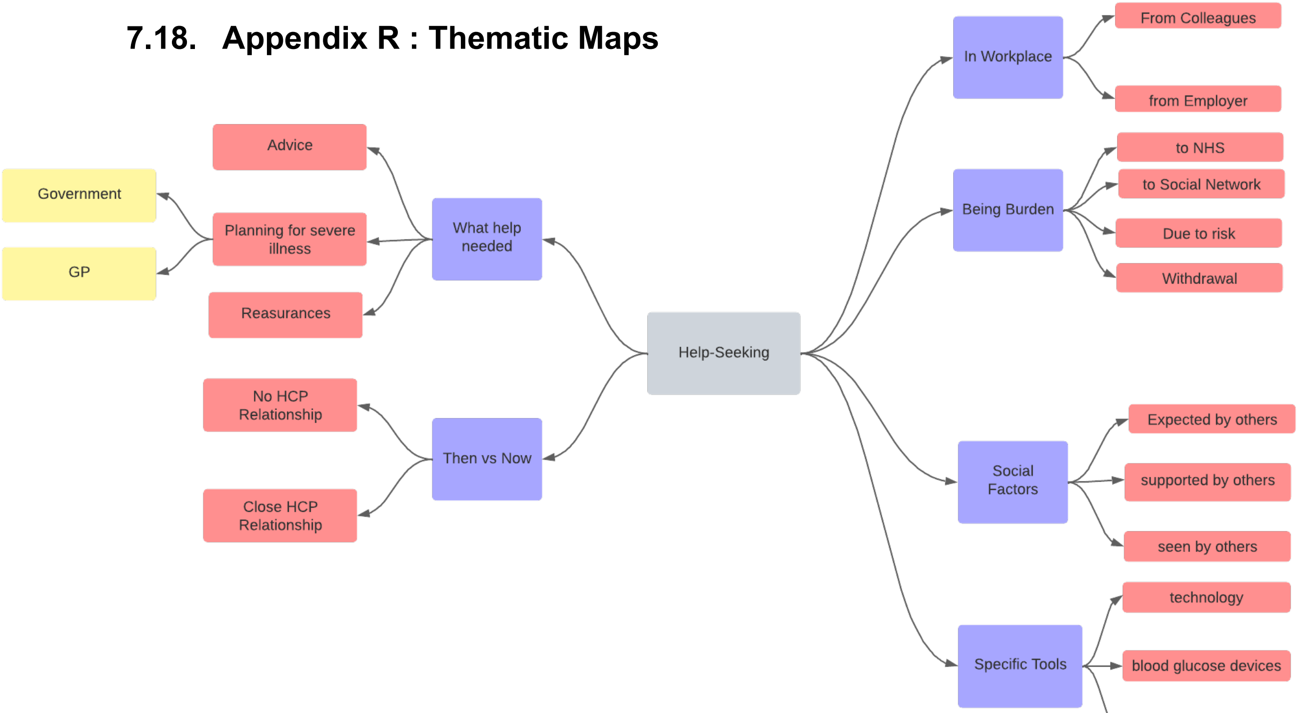
7.17. Appendix Q : Clustering of Codes



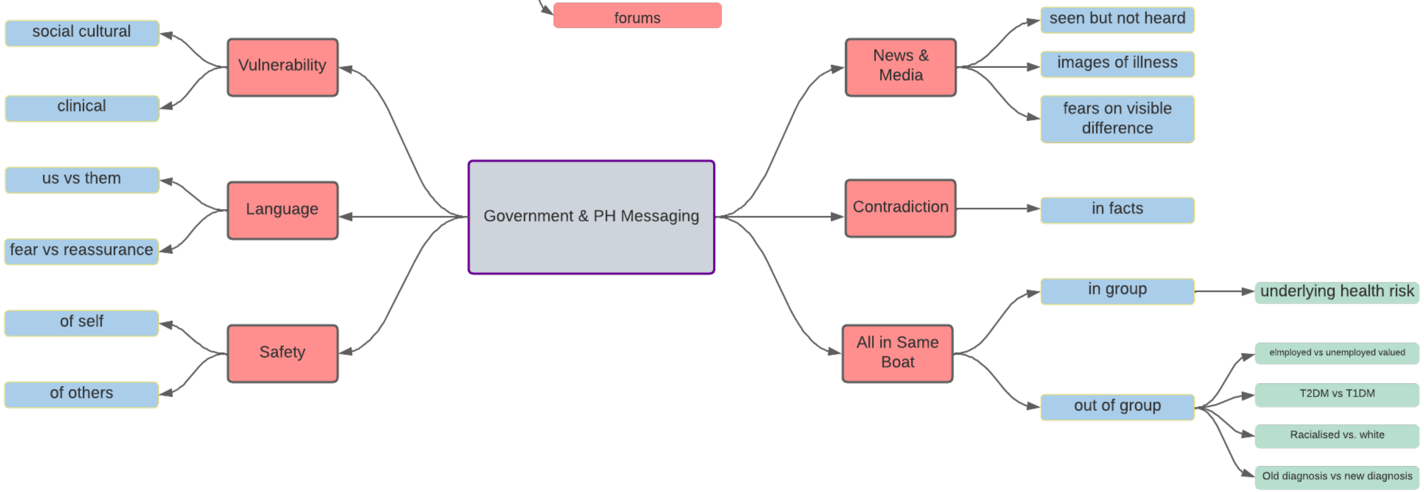
Initial stages of clustering of codes downloaded from NVivo13

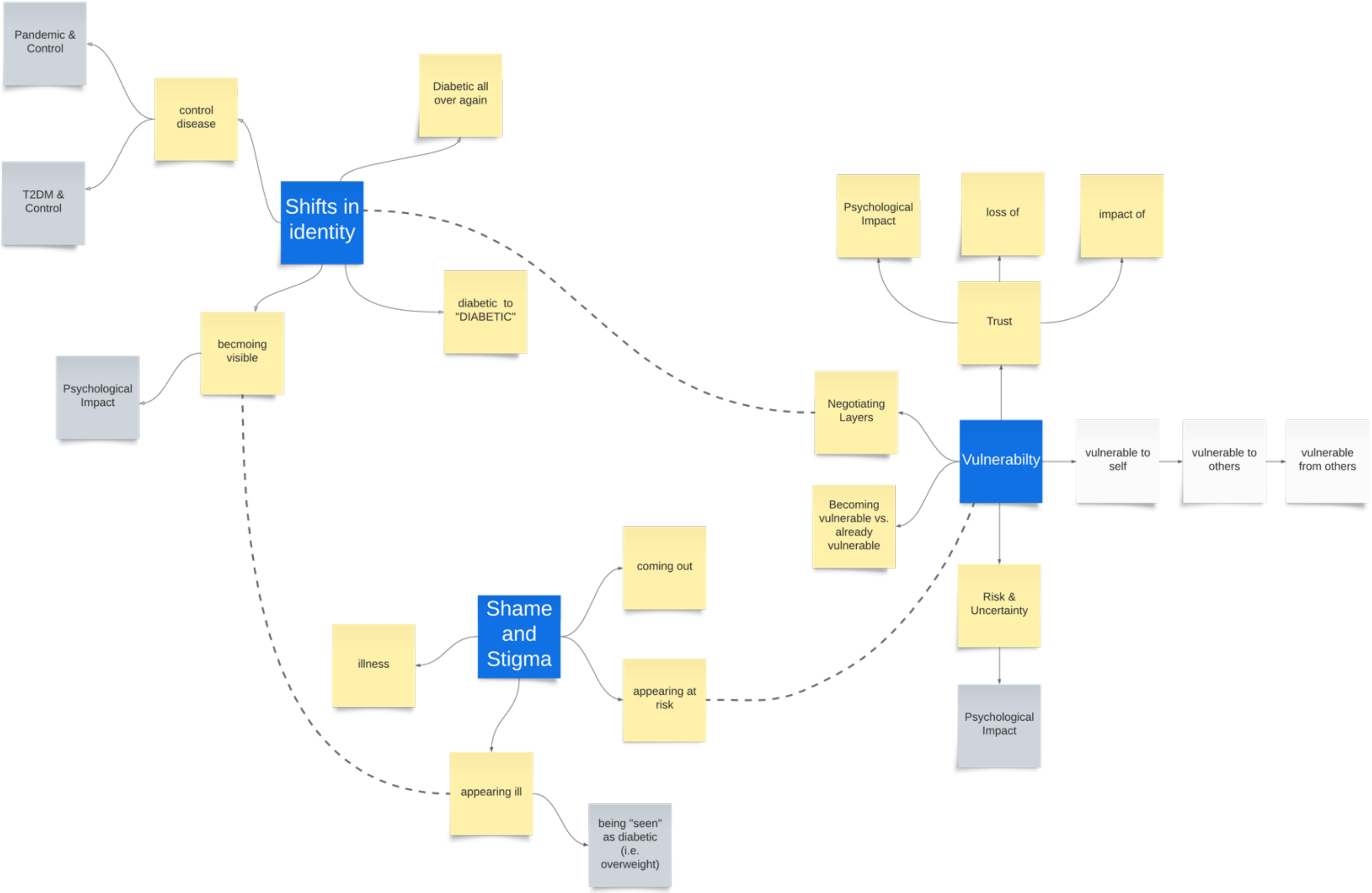


7.18. Appendix R : Thematic Maps

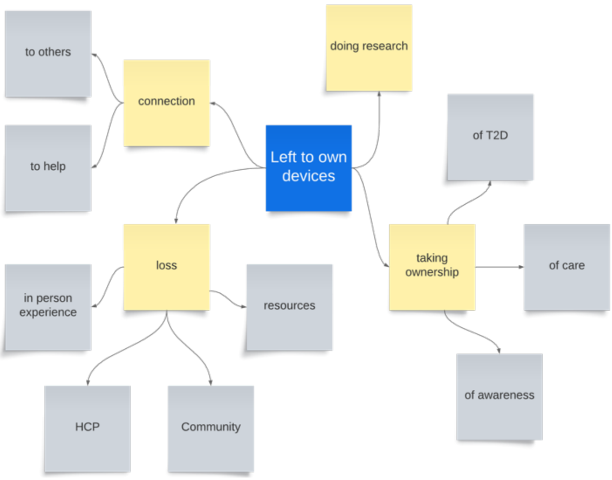


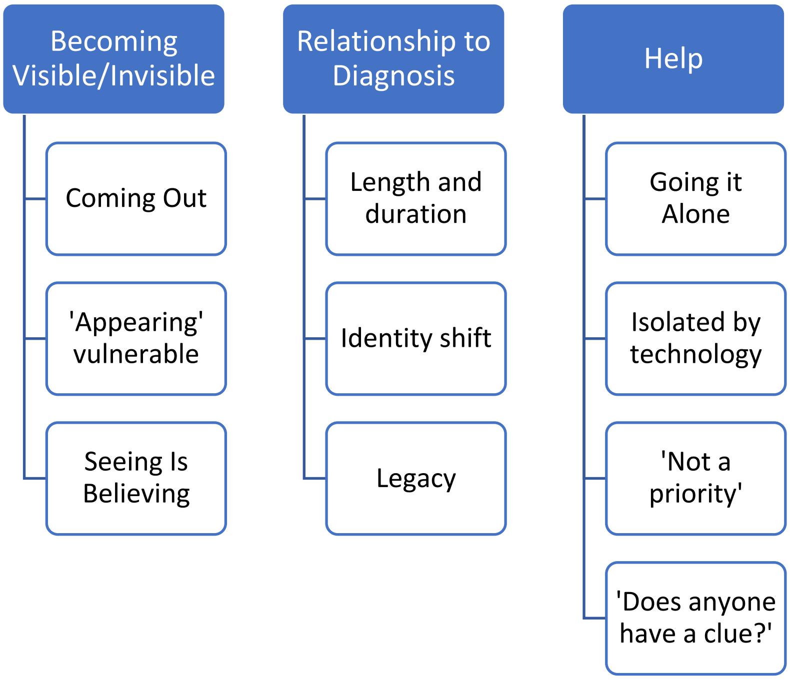
Initial Thematic Map



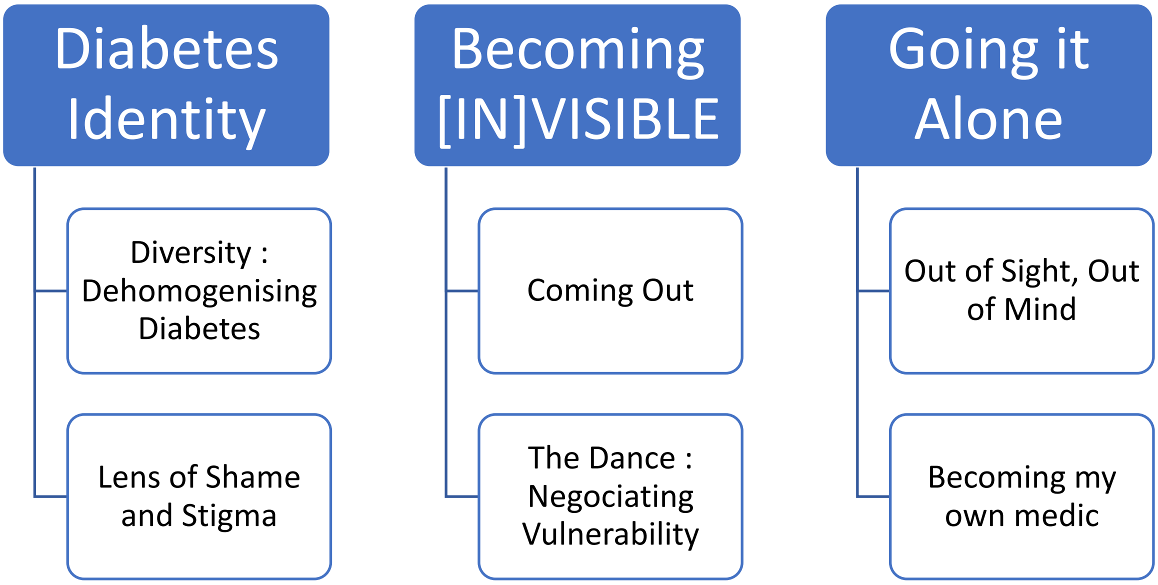


Evidence of Thematic Map Refinement





Final Thematic Map



7.19. Appendix S : Excerpt from Reflexive Journal

Taken from midway through participant interview process immediately following an interview

I was struck today by the pain of the experience from some participants. Very much like my clinical work, it's an extraordinary privilege to be allowed into people's lives in such an intimate way as this. But I suppose my own journey through the pandemic is not necessarily representative of somebody else's. I'd like to hold that in mind when approaching these interviews in recognition of the fact that we're still living through the pandemic. That means different things to different people right now. I notice today how humour might be used as a way of staying away from the discomfort of the experiences being recounted. Really understandable, but I notice my own frustration at wondering whether the ‘quality of the data’ was being in some way impaired because of this. I need to think more about this expectation of quality and beliefs around a ‘good interview.’ I'm wondering how this is experienced by participants, and recognise that being given a voice in these interviews has been described as validating and an opportunity to unload some of the frustration. Am i doing enough, then, in terms of validating these experiences and is there more that I could do. Or should do? Where does the researcher end and the therapist begin. Something I'd like to take to supervision with Trish.

I'm noticing too, the challenge of actively listening and truly following the participant as I'm halfway through my interviews now. I sometimes wonder if I'm seeking confirmation from previous participant experiences rather than remaining available to what is happening in this moment. I'm also thinking about the importance of active listening and reflecting back to participants not only to ensure that I have understood properly and fully their experiences, but also thinking about that idea of validation and how to bring more of that into the experience for participants must also benefiting the quality of the research. Funny I keep using this word ‘quality.’

Each interview ends with me wondering about what I missed, what I didn’t ask, where I might not have allowed enough time for exploration. Perhaps it would be worth starting each journal entry with an acknowledgement of what went well and key helpful learnings and then return to that section before each interview to help with managing nerves. Focus on what feels exciting and valuable in what emerges.

My takeaway from today was thinking about the role of memory, and the way that interviews are excavating these memories but in quite a chaotic way as time and the strangeness of the pandemic is emerging through the interview. With participants connecting events and revising their reflections based on recollections as they emerge during this process. I need to think about the impact of that in terms of transcription and coding and ensuring that the data is well structured and that I am thoughtful in terms of connecting those experiences meaningfully.