Portfolio 1: Major Research Project

The Role of Experiences of the Body and Embodiment in Type 1 Diabetes and Disordered Eating

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Abstract

Type 1 Diabetes and Disordered Eating (T1DE) is a term used to describe the presence of disordered eating patterns that are specific to those with Type 1 Diabetes. Research has highlighted that conventional eating disorder treatments are limited in their effectiveness for this group and specific clinical interventions and resources are lacking. Whilst T1DE is not recognised as a formal diagnosis, growing research has highlighted the complex and unique nature of the experiences, specifically, proposing the role of diabetes-specific factors.

This Constructivist Grounded Theory study took an explorative approach to understanding how people with T1DE perceive their physical body and its relationship to their identity and the social world. 17 people with lived experience of T1DE engaged in semi-structured interviews which were analysed to construct a theoretical understanding of their embodied experiences.

A theoretical model is presented which suggests a dynamic interplay of processes relating to the body, the self, and the relational world which underlie disordered eating in this group. The findings indicated that these processes were intrinsically linked to experiences of diabetes and diabetes management. These experiences appeared to drive an ‘othering’ of the physical body which created a disconnect between participants and their multifaceted selves. A unique process of ‘redefining’ control was constructed, and a secondary process of finding validation in the body was proposed. This secondary process became a powerful reinforcer and was considered to be key in driving disordered eating.

Clinical and theoretical implications are reviewed and early indicators of potential sub-variations within the theoretical model are discussed.

1.0. Introduction

1.1. Chapter overview

This chapter introduces the research scene ahead of the exploration of embodied experiences of people with Type 1 Diabetes and Disordered Eating (T1DE). I will outline my epistemological stance and relationship with the research topic. The research is then placed in context by providing a broad summary of the current and dominant understandings of Diabetes Mellitus, the physical body, and disordered eating. I then summarise how 'T1DE' has started to develop within the literature and is becoming identified as its own field.

1.2. Setting the scene

The term T1DE (pronounced 'tide') is not widely known, even within psychology and health fields, despite being a term which spans both physical and psychological experiences. My clinical work has taken me into varying health contexts, especially as a psychology clinician in physical health. I vividly remember meeting a patient in a hospital who presented acutely unwell with diabetes-related complications. After much liaison with puzzled and frustrated professionals, myself included, it was queried whether this patient may have an Eating Disorder (ED) and the subsequent unclear treatment route became quickly apparent despite a series of significant risks. Years on, I have worked alongside diabetes teams and engaged in my own reading and exploration about this seemingly arcane experience, but have found these wonderings have led only to more questions about these 'concurrent conditions'. I use this phrase questioningly as I noticed how, both clinically and theoretically, this experience has been approached as 'co-morbid' suggesting two separate experiences (i.e. diabetes *and* ED). This separation has seemed to lead to stuck-ness, with neither field feeling able to adequately account for the needs. I have wondered whether T1DE may then be better understood as a distinct phenomenon of itself, warranting its own research exploration, albeit utilising, rather than dismissing, established understandings of both diabetes and EDs to guide the journey.

1.3. Researcher positionality and epistemology

1.3.1. Epistemology

I enter the research with a critical realist social constructionist (or moderate constructionist) approach towards psychological and social knowledge (Harper, 2011). Like more relativist social constructionist approaches, I am interested in how phenomena are spoken about and situated socially within wider context. Rather than attempting to uncover a claim of pre-existing reality, as in realist approaches, I am interested in how research can build understandings of how knowledge is created in the world, what resources are used to do so, and which constructions hold most power in context (Willig, 2012). The moderate constructionist approach does however look beyond spoken words to reach an interpretation. This means that what is said by people, or participants, is situated within a broader cultural context of which there may be pre-existing realities which influence what is spoken and understood; i.e. context can limit words and actions (Harper, 2011; Willig, 2012). In this way, I hold an ontological position that is critically realist, with an epistemological stance to research that is relativist. This means that whilst I believe there is a pre-existing reality to diabetes, I do not believe that research can provide a mirrored knowledge of this, nor do I believe that diabetes can be separated from the social world.

1.3.2. The place of this research in Clinical Psychology

Wainwright and Turner (2003) discuss the broad relationships between body, self, and society. They conclude a position in which the body is seen as partly a pre-existing reality, but also shaped by context. They discuss how illness or disability can be seen within two states; the physical element independent of human construction, and the social state shaped by human knowledges and experience. Research that may be more typically associated with a physical health field, such as diabetes, can therefore gain important insights from being researched in the context of the mind and the social world. Taking a bridged approach between the research worlds of physical and psychological health can support calls for health and illness to be considered within a biopsychosocial model. This approach is dynamic in nature, accounting for temporal context, interpersonal dynamics, and psychological factors, alongside physiology and biology (Lehman et al., 2017; Wade & Halligan, 2017). Iacovou & Weixel-Dixon (2015) emphasise the specific role of the body as dynamic and relational within the world, proposing that views and experiences of the body are key areas for therapeutic and psychological enquiry.

The physical-psychological interlink is becoming apparent within the National Health Service (NHS), for example the National Institute for Health and Care Excellence (NICE) guidelines for recognition and treatment of EDs now include a sub-section specifically relating to diabetes (NICE, 2020, 1.8.3–1.8.11). The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association, 2013) also now lists insulin manipulation as possible features under Anorexia Nervosa (AN) or Bulimia Nervosa (BN). As understandings of the physical-mental interplay progress, so does advocacy and rationale for specialised research and clarity. Within this field, Allan & Nash (2014) acknowledged the reference to diabetes within the DSM-5 as progress but argued that more distinct recognition of disordered eating within diabetes is needed. Placing this research within clinical psychology supports this growing move towards holistic practice, which is advocated both within the profession and the healthcare system.

1.3.3. Researcher position

Whilst we all have experience of living within a body of varying levels of 'health,' it is important to acknowledge my position as an outsider researcher in relation to my participants with lived experience of T1DE. I have not experienced T1DE, nor have I experienced living with diabetes, any chronic illness, or clinically recognised disordered eating. Whilst I sit as an outsider researcher to the specificity of T1DE, I am aware of the ways in which I may sit on the boundaries of the insider/outsider researcher threshold in other ways. During my life I have developed an understanding of my physical body and its role in my identity; as this research explores roles and perceptions of the body, my own experiences will undoubtably influence my thinking. Secondly, I have worked for 10 years within varying healthcare settings, embedding myself alongside people with varying physical-psychological needs, most notably working in hospitals, diabetes services, acquired brain injury rehabilitation, and currently, cancer and palliative services. My clinical positioning places me as somewhat 'inside' the healthcare system used by patients like those to be recruited in this research, meaning that I am not without pre-existing knowledge or influences relating to this field.

1.3.4. Language and terminology

I will adopt the term T1DE in reference to the community I will be conducting this research alongside. Lived experience consultants have shared the disconnect felt with conventional ED terms, and so using the terms diabetes and ED concurrently felt misrepresentative. Diabetics with Eating Disorders (DWED), a previously operating charity and ongoing established T1DE support forum have expressed support for 'T1DE' and an intention to favour this term (DWED, n.d.). T1DE terminology is evolving and has changed over the very recent years; any other terms used within this write up will be defined when used.

1.4. The research in context

1.4.1. Diabetes Mellitus

Diabetes Mellitus (DM) is a condition in which blood sugar levels become too high, causing several health problems (NHS, 2023a). DM is primarily understood in two variations: type 1 (T1DM) and type 2 (T2DM); although other variations are apparent, including gestational diabetes and Latent Autoimmune Diabetes of Adults (LADA) or 'type 1.5'; the different types require different treatment (Juvenile Research Foundation Ltd, JDRF, n.d.). T1DM is understood as an autoimmune disease in which the body is thought to attack cells in the pancreas, meaning that the hormone insulin is not produced and there is no known way to prevent this (Echeverri & Tobón, 2013; Kahaly & Hansen, 2016; Kawasaki, 2014). Insulin is essential for survival as it is responsible for moving glucose from the bloodstream into cells to be converted into energy; T1DM requires manual administration of insulin, for example, via injection or pump, to replicate the way in which insulin is typically produced by the body. This is required daily and indefinitely.

T1DE is specific to T1DM and the current study will focus only on experiences of people with T1DM. Whilst exploration of disordered eating would certainly be important in T2DM, to attempt to combine the two would do a disservice to both conditions due to the unique nature of each.

1.4.2. T1DM and the physical body

Understandings of the physical body seems key when considering T1DE, given the physiological nature of both T1DM and eating. T1DM impacts the body in many ways; ranging from organ functioning, to visible or felt experiences of the outer body.

1.4.2.1. Bodily functioning

Many early T1DM symptoms are physical in nature, such as frequent urination, increased thirst, and weight loss (Maahs et al., 2010). Diabetes UK (n.d) divide physical complications of T1DM into chronic and acute manifestations. Chronic complications develop gradually but with significant risk, including problems with vision, poor blood circulation, and nerve damage. Acute complications present suddenly, including hyperglycaemia (high blood sugar); hypoglycaemia (low blood sugar); and Diabetic Ketoacidosis (DKA). DKA is when ketones, which are harmful substances, build up in the blood due to lack of insulin; it is life-threatening and a medical emergency (NHS, 2023b). Mental health difficulties have been associated with many of these experiences, for example the distressing impact of hypoglycaemia (Trief et al., 2013) and anxiety relating to bodily abilities, such as child-rearing (Vanstone et al., 2015).

1.4.2.2. The seen body

Elements of living with T1DM can be seen to draw attention to the physiological body. Watts et al., (2010) highlighted the visible indicators of T1DM, with one of their participants describing their body as “a dartboard”. Manifestations of T1DM are often reflected by the outer body, for example, unexplained weight loss, repeated infections, and unhealed cuts (NHS, 2021a). Newly developing technologies are emerging for patients which may be visible and attached to the outer body, such as insulin pumps, continuous glucose monitoring (CGM), or flash monitors (NHS, 2021b).

1.4.2.3. Managing the body

T1DM self-management demands significant focus and manual interaction with the physical body. People with T1DM are required to regularly monitor blood sugar, adjust food and carbohydrate intake strictly, and manually administer insulin to simulate this bodily process that most others do not even think about. It is maybe therefore unsurprising that people with T1DM report stress, fear, guilt, shame, and a sense of failing in their management of their physical being (Davidson et al., 2004; Trief et al., 2013; Watts et al., 2010).

1.4.3. The T1DM body in the world

Philosopher Merleau-Ponty suggests that humans both have a body and *are* a body; in that the body is not a static vehicle which holds the mind, but rather humans in themselves are bodily beings (as cited in Iacovou & Weixel-Dixon, 2015). Iacovou & Weixel-Dixon (2015) expand by proposing that the body not only provides a viewpoint for the world, but provides a way for others to view, construct, and interact with said body or person. Given the physical nature of T1DM outlined above, I am curious about how the T1DE body is perceived and understood within the world.

Physical bodies are an integral part of self-identity and by engaging in certain body practices or disciplines, a person is maintaining, structuring, or restructuring both their body, and their identity (Balfe, 2009; Shilling 2012). This idea, known as ‘body projects’ aligns people with their valued identities through bodily regimes and behaviours. For example, lifting weights can support identity via a ‘strong’ or ‘masculine body’; or binge drinking can support identity via a ‘student body’. This supports the notion of the body having some individualised construct, but being heavily influenced by social, historical, and cultural factors. Body constructs, e.g. a ‘feminine body’, ‘healthy body’, or ‘young body’, are all influenced by external context, such as social discourse, media representation and culture and can act to drive a person towards certain body standards. Shilling (2012) discusses that whilst the body can be facilitative towards preferred identity, it can also be constrained by its limits, for example, aging, fatigue, and death. Chronic illness and health complications can present such limits and may act as obstacles to the preferred ‘body projects’ of individuals.

Balfe (2009) explored the ‘body projects’ of students with T1DM and found them to be similar to those of their non-diabetic peers, i.e. preferring to identify with a normal ‘student body’. However, for some, diabetes sabotaged their efforts towards this ‘student body’, for example by experiencing hypoglycaemic attacks in public, or needing to limit alcohol or junk food during group socials. For others, blood glucose testing misaligned with the image associated with their preferred ‘student body’ and despite knowing the importance of monitoring and managing their blood sugar, regimes were delayed or done only in private to protect their portrayed identity. This highlights the unique experience of T1DM in which an extra dimension, or limit, impacts the execution of ‘body projects’ or aligning of preferred identities. I wondered about how these experiences might impact behaviours relating to the body, and in particular one of the most vital and interlinked behaviours relating to the body: eating.

1.5. Situating T1DE in the literature

1.5.1. Food and eating in T1DM

When considering the physical body in T1DM, there is a particular focus on weight, food, and eating. Weight fluctuations are common and often people may lose significant weight prior to T1DM diagnosis, and subsequently gain weight upon diagnosis and commencement of an insulin regime (Diabetes UK, n.d). Furthermore, monitoring of glucose levels and the required scrutinising of food intake to calculate insulin dosage draw a continual focus on eating and food. Arguably, this presents people with T1DM with a unique dynamic to food and eating, requiring increased focus and attention.

I was curious about how this increased focus on food may impact both the way in which healthy eating may be considered for this population, and how disordered eating or EDs can be identified or understood.

1.5.2. Defining T1DE

Whilst there is no formal differentiated diagnosis for ED or disordered eating in T1DM, Allen (2015) presented findings to suggest that those with these experiences often do not feel that conventional ED labels or diagnoses describe their experiences accurately. In this study only 4% of participants responded to indicate that they related to a term that was not specific to T1DM, with most answering that they best related to the term ‘diabulimia’ either on its own, or alongside another term such as AN or BM. Diabulimia refers specifically to the act of omitting or restricting insulin in the context of disordered eating. As research has progressed, and as previously mentioned via lived experience channels, T1DE has appeared to become more utilised in recent years as it encapsulates a slightly broader disordered eating experience.

Recently, robust guidance has been developed within the NHS to support assessment of this population which explicitly uses the term T1DE, and advocates for this term to be taken forward as a diagnostic term (Alicia et al., 2021). This guidance formed part of a national pilot for an integrated T1DE pathway within the healthcare system. The guidance presents suggested diagnostic criteria for T1DE, which I have used to support my definition and understanding of T1DE. The definition proposes that all three of the below criteria are met:

1. Experience some extent of disturbance in relation to body weight or shape
2. Engagement in recurring direct or indirect insulin omission or other compensatory behaviours (such as food restriction, over-exercising, self-induced vomiting, or laxative use)
3. The insulin restriction or compensatory behaviours result in harm to health, significant diabetes distress, or impaired functioning.

1.5.3. Prevalence of T1DE

A wealth of research suggests that people with T1DM have an increased likelihood of experiencing disordered eating or diagnosable EDs than the non-diabetic population (Colton et al., 2015a; Doyle et al., 2017; Goebel-Fabbri, 2009; Hanlan et al., 2013). Whilst reported prevalence rates are inconsistent, Diabetes UK (2019) report that around 2 in 5 people with T1DM experience disordered eating; the charity describes disordered eating as an unhealthy relationship and fixation on food and weight which leads to unhealthy behaviours, which is separated from diagnosable eating disorder conditions. The nature of EDs in the general population has often been understood to involving secrecy, concealment, and denial (Smart & Wenger, 1999; Vitousek et al., 1998). The possibility of such secrecy, along with the already complex and closely managed relationship with food in T1DM, means that the prevalence of ED or disordered eating in the T1DM population may be higher than what is known or reported.

In line with this identified prevalence and the consideration of distinct diabetes-related features, the use of screening for disordered eating within T1DM has gained growing attention, for example the Diabetes Eating Problem Survey (Markowitz et al., 2010).

1.5.4. Conventional ED approaches and T1DE

As there are limited specialised interventions available for T1DE, patients are typically seen within diabetes and/or ED services separately, with little collaborative working between these physical and mental health teams (Partridge et al., 2020). Subsequently, poorer outcomes and higher dropout rates have been found for people with T1DM accessing conventional ED support (Colton et al., 2015b; Custal et al., 2014). Allan (2017) outlines the multitude of ways in which T1DM monitoring deviates from typical ED monitoring and management; for example to account for blood glucose levels, ketones, glucose toxicity and dangerous potential consequences of T1DM such as cerebral oedema (brain swelling caused by DKA). It is therefore maybe unsurprising that conventional treatments are limited in their usefulness for this population.

This indicates that the needs of T1DE are not being met by the current ED treatment models, which are actively used in the current healthcare system. Indeed, in a literature review, Clery et al. (2017) concluded that ED interventions for people with T1MD were yielding either only small changes or no improvement at all in diabetes control or ED symptomology.

Due to the identified differing needs of T1DE from the offer of conventional ED approaches, I will not explore the specificities of ED treatments here, but will highlight the identified similarities and differences in needs below. A recent narrative review of current understandings and future directions of ED treatment has been conducted by Feng et al., (2023) which can be consulted to direct reading on ED interventions.

1.5.4.1. Aligned features of T1DE and EDs

In a theoretical model proposed by Treasure et al., (2015) which was based on a review of existing literature, some similarities were noted to conventional ED understandings. These included: perfectionism, weight concerns, poor mood regulation and interpersonal difficulties. This importantly highlights that ED understandings may still be useful for this population and are not to be dismissed, but rather tentatively held or build upon to build richer and more specific understandings.

1.5.4.2. Misaligned features of T1DE and EDs

There are features distinct to T1DE from EDs, for example, insulin manipulation which was demonstrated by Allen (2015), who found that of 95 participants questioned about the nature of their disordered eating, 95.9% had omitted or manipulated insulin, a feature only possible in T1DM. These fundamental differences in how disordered eating manifests may account for why the conventional treatments for ED seem less effective in supporting this population. In addition to actively omitting doses of insulin, people with T1DE may also make extreme dietary restrictions to indirectly reduce the need for insulin administration (Alicia et al., 2021). Whilst food restriction may appear a similar feature, this underlying link to insulin regime changes suggests a fundamentally differing nature for those with T1DE.

The above-mentioned theoretical model by Treasure et al., (2015) highlighted areas of distinction from other forms of EDs in addition to the similarities. These differences included insulin mismanagement and a proposed phenomenon of ‘food addition’ or disinhibited eating specifically related to low blood glucose.

1.5.5. Distinguishing T1DE?

Considering the above literature relating to distinct T1DE features, poor outcomes to conventional treatment, and diabetes-specific food practices has led me to revisit my initial hunch from my clinical work introduced at the start of this chapter. This was the idea that the T1DE phenomenon may be better understood as a field of its own, potentially necessitating exploration in its own right, as opposed to a model of two co-morbid conditions.

These wonderings seem to reflect a shift in the language and positioning of these experiences within the literature and clinical landscape, for example Ward et al., (1995) used the term "double disabled" and talked of patients having "both diabetes mellitus and an eating disorder", whilst more recent work in the field, such as that described in section 1.5.2, are using a more specific and singular use of language, such as T1DE, or Diabulimia.

With the growing attention towards a more joined up approach to T1DE, I was left curious of how the phenomenon is clinically understood and treated. This led me to a systematic consultation of the literature which is presented in the next chapter.

2.0 Systematic Literature Review (SLR)

2.1. Chapter overview

This chapter presents an SLR in which I take a more detailed and specific look at the clinical understandings and intervention features of T1DE support; this moves from, but has been fundamentally informed by, the wider breadth of literature included in the previous chapter. I will present the process that I followed for this SLR, followed by a summary of the identified papers and quality appraisal of the literature. Finally, I will present the key ideas and conclusions developed from the synthesis and will identify literature gaps and limitations.

The question I will address is: *“What does the literature say about the nature and features of current intervention for T1DE?”*

2.2. Doing a literature review

Bolard et al., (2017) describe an SLR as a way of appraising and synthesising available evidence to answer a specific question from which relevant conclusions can be drawn. Completing SLRs within Grounded Theory (GT) research is disputed due to deliberation that reviewing the literature has the potential to taint research by situating new data through the lens of earlier or established ideas (Charmaz, 2014). Despite this, it is recognised that researchers have pre-existing experiences and familiarisation with the evidence base; for example, through clinical working or to justify research need during ethical approval applications (Deering & Williams, 2020). They therefore suggest that an SLR can form part of GT research but advise that, particularly in Constructivist GT, researchers should work reflexively to acknowledge, rather than ignore or take as fact, pre-existing knowledges. I kept a reflective journal throughout the SLR process and made attempts to keep some distance between the SLR and research analysis, for example, completing the SLR process and write up at a different time point to my research data collection and analysis.

2.3. SLR process

2.3.1. Search strategy

This SLR aims to take a specific look at the nature of current T1DE interventions and treatment and is restricted to papers with this focus. The synthesis aims to build upon the important literature presented within the introductory chapter which highlighted the prevalence of disordered eating within T1DM; the risk factors associated with T1DE; and the poor outcomes of conventional ED therapy in T1DE.

The search was conducted between August 2022 – March 2023 using the databases Scopus, PsycArticles and Pubmed, accessed via the University of Hertfordshire. Manual searches were conducted with weekly email alerts set to notify of any new research identified from the saved criteria. These databases were chosen as relevant as they encapsulate medical, behavioural, psychological, and applied social sciences which are likely to have interest in the field of the research question. A scoping search via Google Scholar and manual citation checks of relevant papers were conducted. A pilot search was conducted, and terms were refined based on the results returned. Initial searches yielded too many papers that were able to be screened sufficiently within the remit of project timescale (600,000+) and so search terms were refined to narrow the output. The final search terms and inclusion and exclusion criteria used are presented in Tables 1-2.

Table 1

Literature review search terms

Concept 1 **Type 1 diabetes mellitus**	**Concept 2** **Disordered eating**	**Concept 3** **Psychological intervention**
OR type 1 diabetes	OR eating disorder	OR Psychological treatment
OR Type 1 diabetes with disordered eating	OR insulin omission	OR Psychological therapy
OR Eating disorder with Diabetes	OR insulin restriction	OR Psychological provision
OR T1DM	OR anorexia	OR Psychological service
OR insulin-dependant diabetes	OR bulimia	
OR insulin-dependent diabetes	OR diabulimia	
OR T1DE	OR binge eating	
OR type one diabetes	OR restricted eating	

Table 2

Literature review inclusion and exclusion criteria

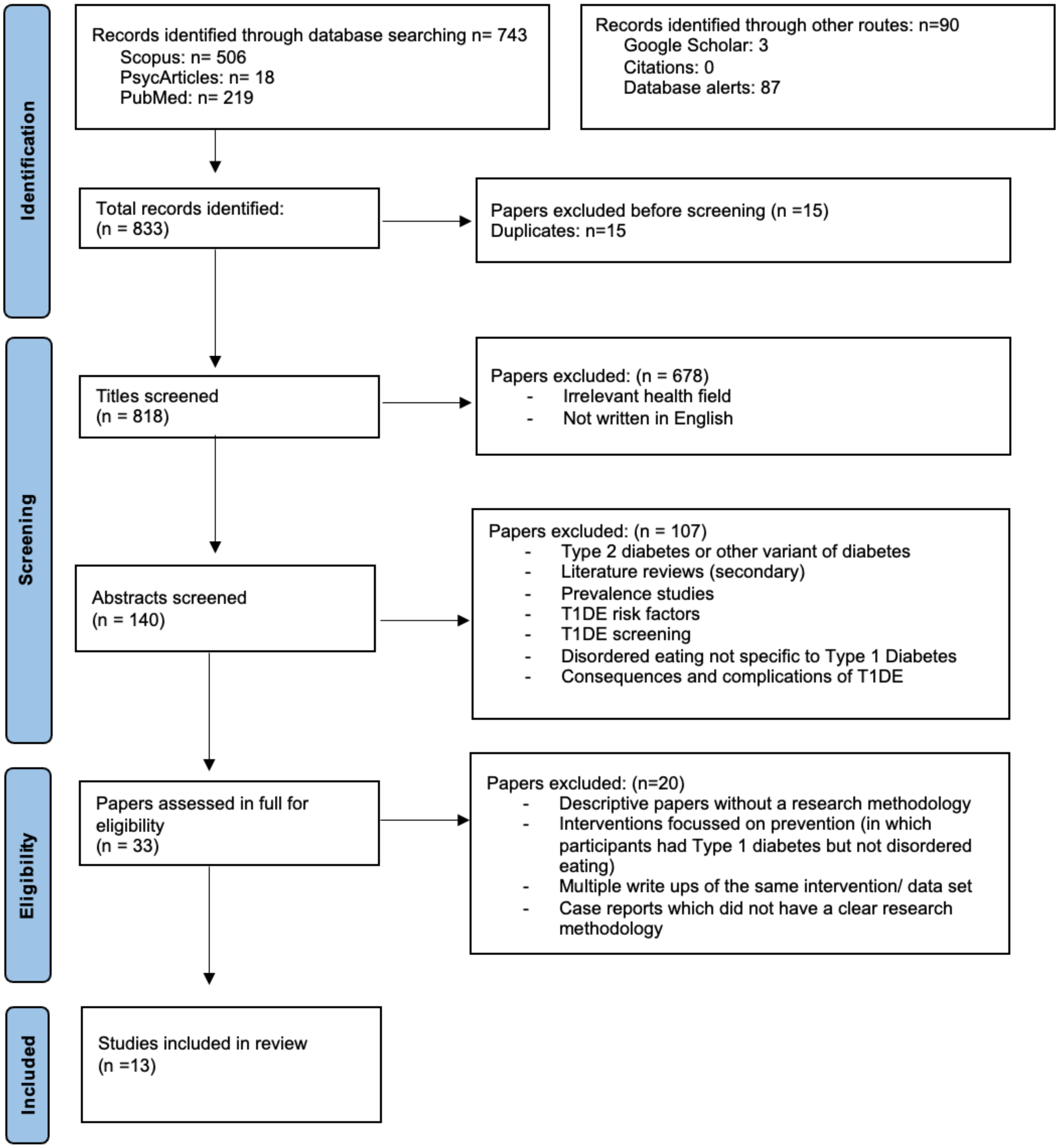
Inclusion	**Exclusion**
Focussed on Type 1 diabetes, not Type 2 or both Type 1 and Type 2	Did not meet inclusion criteria
Experiences of diagnosable eating disorders, and/or non-diagnosed disordered eating	Focussed on prevalence of T1DE
Written in English	Focussed on risk factors for T1DE
Published within last 20 years (2002 onwards)	Focussed on screening for T1DE
Empirical research with a clear methodology	Descriptive papers
Focussed on treatment of T1DE	Secondary data – e.g., literature reviews
Focussed on nature of intervention for T1DE	Focussed on participants or patients without disordered eating (e.g. prevention)
Feasibility trials or pilot interventions	

2.3.2. Search results

Using this search strategy, 833 articles were identified and screened via title and abstract, leaving 33 identified as potentially relevant, which were screened in their entirety. Papers were reviewed for inclusion with the supervisory team to ensure consensus and a total of 13 papers were included in the final SLR. The flow-diagram in Figure 1 provides a breakdown of literature identification as per the inclusion and exclusion criteria using PRISMA guidance (Page et al. 2021).

Figure 1

PRISMA 2020 Flow diagram of Paper Selection



The identified papers included four quantitative papers (Boggiss et al., 2020a; Dickens et al., 2015; Merwin et al., 2021; Takii et al., 2003), seven qualitative papers (Coleman & Caswell, 2020; Hage et al., 2023; Harrison et al., 2021; Hastings et al., 2016; Hillege et al., 2008; Zaremba et al., 2022; Zaremba et al., 2020) and two papers outlining intervention or trial protocols which did not use participants (Boggiss et al., 2020a; Partridge et al., 2020). Table 3 presents a summary of each paper, summarising the aims, participants, findings, strengths and limitations. Within the 13 papers, two reported on the same intervention trial (Boggiss et al., 2020a; Boggiss et al., 2020b), upon review it was decided that both would be included as they offered novel and differing information, i.e one provided in-depth detail of the intervention protocol, whilst one reported the feasibility and acceptability trial outcomes. Both therefore offered uniquely important information helpful for the review question. Three of the identified SLR papers reported on separate parts of a bigger ongoing funded research programme (Harrison et al., 2021; Zaremba et al., 2022; Zaremba et al., 2020) but described different arms of the research. The 13 papers are summarised in Table 3.

Table 3

Summary of SLR papers

Authors and title	**Aims**	**Participants**	**Design and analysis**	**Key findings**	**Strengths and limitations**
Boggiss, Consedine, Jefferies, Bluth, Hofman & Serlachius (2020a). Protocol for a feasibility study: a breif self-compassion intervention for adolescents with type 1 diabetes and disordered eating.	To describe and explain the aim of examining the feasibility and acceptability of a brief self-compassion intervention for adolescents with type 1 diabetes and disordered eating behaviour.	n = N/A, protocol description. Type 1 Diabetes and moderate-high disordered eating behaviours.	Feasibility study (protocol description). Description of 2 intervention sessions using self-compassion principles – participants to be assigned to self-compassion intervention, intervention, or waitlist.	Rationale for a self-compassion approach to supporting people with type 1 diabetes and disordered eating established.	Strengths: A novel approach of using self-compassion with adolescents with T1DE, addresses the gap in 'clinically usable tools' for the T1DE population. Limitations: limited participant pool to female adolescents therefore generalizability beyond this group to be taken with caution.
Boggiss, Consedine, Schache, Jefferies, Bluth, Hofman, & Serlachius. (2020b)* A brief self-compassion intervention for adolescents with type 1 diabetes and disordered eating: a feasibility study.	To examine the feasibility and acceptability of a brief self-compassion intervention for adolescents with type 1 diabetes and disordered eating behaviour.	n = 27 Females, adolescents, New Zealand Type 1 Diabetes and moderate-high disordered eating behaviours	Feasibility study. Acceptability assessed via qualitative questionnaires. Feasibility assessed by recruitment metrics and attendance.	Self-compassion was concluded to be a good conceptual fit for type 1 diabetes and disordered eating intervention in adolescence. The intervention content was concluded to be acceptable, but feasibility issues suggested that intervention could benefit by being delivered online to increase accessibility.	Strengths: A novel approach of using self-compassion with adolescents with T1DE, addresses the gap in 'clinically usable tools' for the T1DE population. Limitations: limited participant pool to female adolescents therefore generalizability beyond this group to be taken with caution.

Authors and title	Aims	Participants	Design and analysis	Key findings	Strengths and limitations
Coleman & Caswell (2020). Diabetes and eating disorders: an exploration of 'Diabulimia'.	To explore the views and experiences of people with lived experience of Diabulimia. To increase understanding for healthcare professionals about Diabulimia.	n = 45 42 female, 2 male, 1 non-disclosed gender. Age range 15 – 58 (mean age 32). UK based. Diabulimia (insulin restriction/ omission)	Online questionnaires (mixed quantitative assessment measures and open-ended qualitative questions). Thematic analysis.	Psychological treatment should be part of the treatment for Diabulimia, an emphasis on the understanding of both the physical and psychological was identified. Themes important for treatment related to: - Weight and appearance concerns - Past trauma - Role of relationships - Challenges relating to diabetes acceptance	Strengths: First-hand experiences of people with lived experience. Exploration of an under-researched population. Online questionnaire was relatively quick and allowed a somewhat varied sample. Limitations: Non- female genders underrepresented within the sample. Online questionnaires mean that data was limited in richness – authors suggest interviews for future research.
Dickens, Haynos, Nunnemaker, Platka-Bird & Dolores (2015). Multidisciplinary residential treatment of type 1 diabetes mellitus and co-occurring eating disorders.	To examine the outcomes of a multidisciplinary residential treatment for people with Type 1 diabetes and an eating disorder, and to examine impact of treatment duration.	n = 29 Female, USA based. Type 1 diabetes and Eating Disorder diagnoses	Analysis of archival data between 2008 – 2012 (blood glucose data, psychological symptoms and eating disorder symptomology as per outcome measure data).	Statistically significant improvements in blood glucose, eating disorder symptomology and general psychiatric concerns with moderate effect size following inpatient multidisciplinary treatment. Indicates association of positive outcomes and safe facilitation of intuitive eating approach in T1DE, but more research needed.	Strengths: Provides evidence to align with a previously un-tested recommendation of multidisciplinary working for T1DE. Limitations: was not comparative to other approaches and level of care. Participants were all female gender.

Authors and title	Aims	Participants	Design and analysis	Key findings	Strengths and limitations
Hage, Nilsen, Karlsen, Lyslid, Wennersberg & Wisting (2023) I am not alone: A qualitative feasibility study of eating disorders prevention groups for young females with type 1 diabetes.	To qualitatively explore the feasibility of eating disorder prevention groups for people with Type 1 diabetes.	n = 17 Female, mean age 26.6. Norway based. Type 1 diabetes (in the context of Diabetes body project group).	Focus groups using a semi-structured interview guide. Thematic analysis.	One overarching theme *'the benefit of meeting peers with lived experience of T1D and body image concerns'* and four themes within this were identified: *'The need for an integrated focus on diabetes'; 'Personal relevance'; 'Providing sufficient balance between structure and flexibility'; 'Enabling a different perspective'* Positive responses to group intervention targeting eating disorders in T1DM found.	Strengths: first-hand accounts and feedback from an under-researched population and as part of a broader intervention (Diabetes Body Project). Limitations: Participants named the impact of the COVID-19 lockdown which was in place at the time of the research and may have impacted findings, especially those relating to social factors.
Harrison, Zaremba, Brown, Allan, Konstantara, Hopkins, Treasure, Ismail & Stadler (2021). A cognitive behavioural model of the bidirectional relationship between disordered eating and diabetes self care in people with type 1 diabetes mellitus.	To develop a CBT model of the development and maintenance of disordered eating in type 1 diabetes. To explore recovery and resilience factors to inform theoretical models.	n = 23 Female, UK based. Type 1 diabetes and disordered eating AND Type 1 diabetes (no disordered eating)	Semi structured interviews. Grounded theory and development of individual cognitive-behavioural formulations to inform theoretical models.	A development and maintenance model of disordered eating in type 1 diabetes and disordered eating was produced in which cycles of thoughts, feelings and behaviours were outlined which included themes of perfectionism, difficult diabetes diagnosis experiences and sensitivity to daily management routines. A resilience model was also developed to identify protective or recovery factors which included a 'good enough' mentality to diabetes management, self-compassion, and integrating diabetes as one part of overall identity.	Strengths: The first model developed to conceptualise T1DE, drawn from first-hand experiences and similarities drawn to existing eating disorder literature. Looked at both disordered eating development and protection/resilience. Limitations: All female sample. Volunteer sample.

Authors and title	Aims	Participants	Design and analysis	Key findings	Strengths and limitations
Hastings, McNamara, Allan & Marriott (2016) The importance of social identities in the management of and recovery from 'Diabulimia': A qualitative exploration.	To explore how group membership and social identities contribute to and hinder recovery from disordered eating in type 1 diabetes.	n = 13 Female, ages 18-67, UK based. Diabulimia (insulin restriction/ omission)	Focus groups with semi-structured open-ended interview schedule. Thematic analysis.	The findings showed that group membership and shared identity can be important in supporting recovery, but that groups can have damaging effects if not well managed. Superordinate themes: *'Not like everyone else'; 'Shared identity online promotes recovery'; 'Threats to recovery'; 'Recovery outside of the Diabulimia group'.*	Strengths: The study moves beyond looking at individual factors for challenges to engagement with treatment and provides evidence to the novel idea of the importance of social relationships as actively part of intervention. Limitations: The study relied on retrospective accounts from participants about group membership. Limited to insights from the diabulimic group and doesn't explore wider networks of the participant. All female sample.
Hillege, Beale & McMaster (2008). The impact of type 1 diabetes and eating disorders: the perspective of individuals.	To describe the perspective of living with both type 1 diabetes and an eating disorder.	n = 4 Female, aged 18 – 30, Australia based. Type 1 diabetes and Eating Disorders	Semi-structured interviews – secondary analysis of 4 cases from a broader longitudinal study of 27 participants. 4 cases selected for secondary analysis due to reporting co-morbid type 1 diabetes and an eating disorder. Case analysis.	The results proposed that people with concurrent T1DM and ED had challenges in managing physical, social, emotional and relational dimensions. Conclusions drawn include that people with T1DE need to be given a 'whole person' approach to treatment.	Strengths: Rich and first-hand accounts of experiences. Limitations: Small sample size. All female sample.

Authors and title	Aims	Participants	Design and analysis	Key findings	Strengths and limitations
Merwin, Moskovich, Babyak, Feinglos, Honeycutt, Mooney, Freeman, Batchelder & Sangvai (2021). An open trial of app-assisted acceptance and commitment therapy (iACT) for eating disorders in type 1 diabetes.	To pilot a novel intervention underpinned by app-based ACT for people with T1DE and assess acceptability and feasibility for implementation. Secondary aim to assess functionality of the app and explore outcomes on diabetes management and disordered eating behaviours.	n = 20 Female, 79% white, USA based. Type 1 diabetes and 'clinically significant ED symptomology'	Pilot study – 12 session intervention of iACT. Feasibility and acceptability assessed via quantitative outcome measures.	iACT treatment was concluded to be acceptable and feasible as a T1DE intervention. Increased psychological flexibility and pursuit of personal values were reported. Large effect sizes for changes in diabetes distress, diabetes self-management and ED symptoms were found.	Strengths: Provides support for a feasible and acceptable intervention for T1DE which is accessible via digital form. Limitations: The iACT was paired alongside individual therapy, which was not assessed as part of the research and so conclusions cannot be drawn around which part of the intervention were effective. As the study was looking at acceptability and feasibility, further research needed into the longer term follow up effects. All female sample.
Partridge, Figueiredo, Rouse, Cross, Pinder, Ryder, Bennett & Stacey (2020). Type 1 diabetes and disordered eating (T1DE): the compassion project – Wessex.	To describe an NHS England funded pilot whereby the diabetes teams and eating disorders teams in Wessex work side by side developing a service specifically for people with T1DE.	n = N/A, pilot description Type 1 diabetes and disordered eating	Service development pilot description. No analysis of data.	The possibility of safe and holistic care for people with T1DE by drawing on the expertise and knowledges of two distinct teams (ED and diabetes) despite working in differing localities with different electronic patient systems.	Strengths: The authors describe practical ways of co-working to support T1DE patients and draw upon integrative recommendations to support these patients, whilst also acknowledging barriers and how these were overcome. Limitations: A descriptive article which does not have any formal analysis of outcomes.

Authors and title	Aims	Participants	Design and analysis	Key findings	Strengths and limitations
Takii, Uchigata, Komaki, Nozaki, Kawai, Iwamoto & Kubo (2003) An integrated inpatient therapy for type 1 diabetic females with bulimia nervosa: a 3 year follow-up study	To describe and assess an integrated inpatient therapy for patients with type 1 diabetes and recurrent binge eating for its effectiveness with females with bulimia nervosa	n = 19 Female, adults (mean age 23.8) Japan based. Bulimia nervosa	Assessment of an integrated inpatient intervention Analysed via outcome measures including physical (HbA1c, BMI) and psychological (disordered eating, anxiety)	Findings provide support for the provision of inpatient treatment for bulimia nervosa in people with type 1 diabetes	Strengths: researched spanned over 3 years allowing gathering of follow up data. Data looked at both physical and psychological outcomes. Limitations: not comparative to other interventions. Limited to people with bulimia nervosa and so cannot be generalised to other forms of disordered eating. All female sample.
Zaremba, Watson, Kan, Broadley, Partridge, Figuereid, Hopkins, Treasure, Ismail, Harrison & Stadler (2020). Multidisciplinary healthcare teams' challenges and strategies in supporting people with type 1 diabetes and disordered eating.	To explore and examine the challenges faced and strategies used by healthcare teams when treating people with type 1 diabetes and disordered eating	n = 29 Diabetes professionals (n = 16) and eating disorder professionals (n = 13). UK based.	Focus groups using a semi structured interview guide (4 groups). Thematic analysis.	Concluding findings that professionals identified the biggest challenges as a lack of: specific diagnostic criteria, evidence-based guidance, screening, training, and interdisciplinary support. Themes relating to challenges faced by healthcare professionals: *'Healthcare professional challenges'; 'Patient specific challenges'; 'Healthcare system challenges'.* Themes relating to strategies in delivering care: '*Training and resources*' and '*Strategies*'.	Strengths: in depth data gathered from two distinct disciplines working closely with the T1DE population. Findings are directly being fed into a wider intervention development and is supporting co-design and development of interventions via first-hand accounts. Limitations: As clinical teams vary by locality, generalisation of experiences beyond the current teams should be taken with caution.

Authors and title	**Aims**	**Participants**	**Design and analysis**	**Key findings**	**Strengths and limitations**
Zaremba, Robert, Allan, Harrison, Brown, Konstantara, Rosenthal, Pillay, Beckwith, Treasure, Hopkins, Ismail & Stadler (2022). Developing a novel intervention for type 1 diabetes and disordered eating using a participatory action design process: Safe management of people with Type 1 diabetes and Eating Disorders studY (STEADY).	To develop a CBT-based intervention for T1DE using a co-designed approach.	n = 40 Lived experience of T1DE (n =15) Healthcare professionals (n =25), UK based. Type 1 diabetes and disordered eating	Co-design workshop for intervention content. Workshops were transcribed and analysed and then reviewed and converted into an intervention toolkit.	A novel intervention toolkit was developed in co-design with people with T1DE and professionals working in the field.	Strengths: Gathered data from both professionals and people with lived experiences. Used a co-design process in which patients and clinicians provided first hand input into intervention design. The intervention was continually reviewed and adjusted. Limitations: participants were identified as being recovered from disordered eating and so relied to some extent on retrospective or reflective ideas from a position of being in recovery.

2.3.3. Assessing literature quality

Standardised quality appraisal tools were utilised to support the assessment of the quality of all papers. Qualitative studies were appraised using the "Big Tent" Criteria for Excellent Qualitative Research (Tracey, 2010) and quantitative studies and trials were appraised using the Critical Appraisal Skills Programme (CASP) Checklist for Cohort Studies (CASP, 2018) or the Consolidated Standards of Reporting Trials (CONSORT) (Eldridge et al., 2016) (extension to randomised pilot and feasibility trials). Sometimes, the checklists used had a different specificity to the paper I was appraising, for example, the CONSORT checklist used provides guidance for randomised feasibility and pilot trials, however Merwin et al., (2021), were trailing an app-based component of an intervention which used voluntary enrolment, not randomisation. Lancaster & Thabane (2019) suggest in these instances that the checklist can be used, with non-relevant items being ignored or marked as not applicable. In this way, checklists were used to guide and direct my thinking and appraisal and not all items were always appropriate or relevant, and these were consulted alongside my own judgement and appraisal.

Specific appraisal of individual contributions to the field is interlaced within the SLR write up, however this practice aimed to look critically at the literature as a whole and to critically consider its quality and contribution to the empirical field.

Appraisal outcomes using these tools are presented in Tables 4-6, the following key is applied to show the level to which the criteria was considered to be met: (✓✓= criteria evidenced to a high standard ✓= criteria evidenced, — = criteria partially evidenced ✗= criteria not evidenced, **?** **=** unclear if criteria met).

Table 4

Quality appraisal of qualitative SLR papers using Tracey (2010)

Criteria	**Authors, year**						
	Coleman & Caswell (2020)	Hage et al. (2023)	Harrison et al. (2021)	Hastings et al. (2016)	Hillege et al. (2008)	Zaremba et al. (2020)	Zaremba et al. (2022)
Worthy topic	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓
Rich rigor	—	✓	✓✓	✓	—	✓✓	✓✓
Sincerity	— (Transparency met, self-reflexivity not evidenced)	✓	— (Transparency met, self-reflexivity not evidenced)	✓	— No evidence of self-reflexivity or researcher positioning	— Evidence of multiple researchers perspective/ but no explicit reflexivity or positioning	✓
Credibility	✓	✓	✓✓	✓✓	✓	✓✓	✓✓
Resonance	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓
Significant contribution	✓	✓✓	✓✓	✓✓	✓	✓✓	✓✓
Ethical	—	—	✓	—	✓	—	✓✓
Meaningful coherence	✓	✓	✓✓	✓	✓	✓	✓✓

The qualitative literature appraisal shows that generally the papers had strengths in evidencing the researched area as a worthy topic; building resonance via the research; and making significant contribution to the field. This made the papers particularly useful for the current synthesis in which an understanding of the collective contributions to this small research base was sought. The appraisal highlighted limitations in the thoroughness of addressing ethical issues. All papers provided evidence of approval from ethical boards for conducting the research, however, this was often the extent of ethical discussion, and ethical considerations specific to each study were not accessible in the articles, maybe due to limitations on word count. The level of methodological rigor varied across papers. Those that demonstrated rich rigor tended to have semi-structured interview formats and addressed a wide scope of participant experience (e.g, Harrison et al., 2021 gathered rich and thick experiences of both difficult experiences of T1DE, and experiences of recovery and resilience). Those that provided less rigor used online written questionnaires in which follow up and conversational encouragement were not possible (e.g. Coleman & Caswell, 2020) or had small sample size and involved secondary analysis of pre-collected data (e.g. Hillege et al., 2008).

Table 5

Quality appraisal of quantitative SLR papers using CASP Cohort Checklist (2018)

	Authors, year	
Criteria	Dickens et al. (2015)	Takii et al. (2003)
Addressing a clearly focused issue?	✓✓	✓✓
Acceptable recruitment?	✓	✓
Exposure accurately measured?	✓	✓
Outcome accurately measured?	✓	✓
Confounding factors identified?	✗	—
Confounding factors accounted for?	✗	Not named, but highly controlled environment

Complete enough follow up?	N/A retrospective archival data	✓
Long enough follow up?		✓
Clear results?	✓	—
Precise results?	✓	✓
Believe the results?	✓	✓
Results applicable to local population?	**?**	**?**
Results fit with other available evidence?	✓	✗ Very little available at time of publication. Research since has shown differing results.
Implications from study for practice?	✓	✓

Table 6

Quality appraisal of intervention trials using CONSORT (Eldridge et al., 2016)

	Authors, year			
Criteria	Boggiss et al. (2020a)	Boggiss et al. (2020b)	Merwin et al. (2020)	Partridge et al. (2020)
Title (identified as pilot)	✓	✓	✓	✗
Trial design	✓	✓	✓	✓✓
Participants	✓ *planned* criteria	✓	✓	✓ service referrals
Interventions	✓✓	✓	✓✓	✓✓
Objective	✓	✓	✓	✓

Outcomes (method)	✓	✓	✓	✓
Randomisation	✓	✓	N/A voluntary enrolment	N/A
Blinding	N/A	N/A	N/A	N/A
Numbers randomised	N/A	✓	N/A	N/A
Recruitment	N/A	✓	— dates not provided	— referral characteristics
Numbers analysed	N/A	✓	✓	N/A
Outcomes (results)	N/A	✓	✓	— qualitative learning presented
Harms	— states ethical approval but no discussion of harms/risks	— states ethical approval but limited discussion of harms/risks	— states ethical approval but no discussion of harms/risks	— individualized risks assessment/ intervention embedded in treatment. No reference to risks of current pilot service.
Conclusions	✓	✓	✓✓	✓✓
Trial registration	✓	✓	✓	N/A part of wider NHS funded trial. Citation provided for further details.
Funding	✓	✓	✓	✓

As presented in the tables, some elements of these appraisal tools were not applicable to the nature of the papers being appraised, for example, blinding and randomisation items were not applicable in Boggiss et al., (2020a) or Partridge et al., (2020) due to these papers taking a protocol description approach, or in Merwin et al., (2021) due to this trial taking a voluntary enrolment approach to one component of larger intervention, rather than use of randomisation. Partridge et al., (2020) were providing a detailed outline of an NHS-funded pilot service and therefore referred to referral criteria and referral structure, rather than typical research-orientated participant information. Whilst the format of this paper was somewhat differing to the more typically appraised research formats, it was an extremely valuable to the current SLR question, offering practical and practiced insights into current service development for T1DE.

Collective strengths of these papers were the addressing of a clearly defined and specific issue, and the detail of intervention outlined. This was useful for this review which was particularly interested in the features of intervention for a specifically defined population.

The appraisal highlighted that the findings of Takii et al. (2003) appeared dissimilar to other findings in the field. Most notably, this research suggested a need for high therapist intervention including observation and instruction, whilst much of the research in the field advocates for an approach which allows more of the control to be with the patient, or at least equally balanced between patient and professional. I wondered about the reasoning for this which may have included that this research was based in Japan, whilst most other research has been conducting in the UK, USA or Western Europe and therefore may indicate cultural variation in treatments and treatment responses. The paper was also somewhat older than other papers and there may therefore have been a general shift in styles of interventions (i.e. shifting from intensive inpatient treatment to community interventions). As the SLR aims to bring together the literature branching across the field, I considered it important to still include this paper and I considered differing findings to be potentially useful for expanding knowledge of the field, rather than problematic. I also noted how my personal clinical working approach has tended to fall within the approaches described in the countering findings and therefore to exclude this paper would have felt potentially biased or routed in subjective opinion.

Many of the reviewed papers utilised participant samples which covered only a small demographic pool, meaning the findings should be considered and generalised with caution. Examples of this included a lack of non-female gendered participants, the over-representation of white ethnic groups and the limited age range of participants which largely fell within adolescent or young adult age brackets.

As shown, formal research on the treatment and intervention for T1DE is limited, albeit growing within the recent five years. Due to limited research, the SLR relied upon feasibility and pilot studies, along with qualitative explorations of service users and professionals' experiences within the field, to provide an understanding of the current treatment landscape. Whilst this may have led some of the research findings to be considered with caution due to being potentially less robust than full-scale Randomised Controlled Trials (RCTs), these studies were important for inclusion to provide a much-needed insight of the current picture.

2.3.4. Synthesis

A narrative synthesis of the 13 papers was conducted following guidance from Baumeister and Leary (1997), Popay et al. (2006), and Siddaway et al. (2019). The review was interested in using the narrative content of the papers to answer the question relating to the nature of T1DE interventions and did not aim to synthesise statistical findings of the studies. As treatments are newly developing with limited RCTs at this time, the review wished to hear what elements of treatment are currently considered to be important, what ideas and approaches are used to form new treatment pilots, and how patients and professionals experience treatment implementation. Narrative synthesis therefore allowed me to extract and analyse the treatment protocols and intervention descriptions of quantitative studies alongside exploratory findings from qualitative enquiries with both patients and professionals.

During synthesis, I noted recurring themes and prominent ideas whilst familiarising myself with the papers as the first stage. Data relevant to the research question was extracted and prepared for analysis using a template guide on SLR data collection by Li et al., (2019) (Appendix B). The data was then further analysed using coding of relevant sections of the extracted data, using NVivo, and categorised into constructed groups or themes of understanding.

2.4. Synthesis findings

I constructed four groupings of knowledges identified from the SLR synthesis:

- Bringing together knowledges of diabetes and eating disorders
- Taking a system level approach
- Cultivating a validating connection
- Promoting self-compassion and acceptance

2.4.1. Highlighting the limited evidence base

Before outlining these ideas, it is important to note the expression within the literature of the discernible lack of T1DE-appropriate clinically established tools that are accessible to researchers and clinicians. Boggiss et al., (2020b) state their intervention plan aim was to “address the lack of clinically usable interventions in diabetes care” and expressed hopes to build upon “the sparse literature”. Merwin et al., (2021) voiced concerns that “patients are without empirically based outpatient treatment options” in their development of their treatment protocol. Harrison et al., (2021) suggest that the intertwining complexity of the two conditions has led to an inadequacy of attempts to conceptualise T1DE, resulting in this limited evidence base, with Zaremba et al., (2022) suggesting that established ED therapies are none-effective for this group due to incompatibility with T1DM. The studies in this review have all taken important steps to move forwards from this position.

2.4.2. Bringing together knowledges of T1DM and ED

All papers acknowledged the importance of bringing together expertise from both T1DM professionals or communities and ED professionals or communities to some extent. Thematic analysis findings from Hastings et al. (2016) yielded a sub-theme of 'self-distinction from other patients'. Here, frustrations were shared of being treated within diabetes-only or ED-only groups, which were reported as ineffective. The authors reflected upon how this approach represented the viewing of T1DE as two distinct diagnoses, rather than a complex phenomenon of itself. 9 of the 13 papers took this idea of collaboration as the central, or one of the central, focuses of the paper, which displays the emphasis within those in the field to challenge this existing view of T1DE. Zaremba et al. (2022) even took this idea as part of their research design by inviting both ED and T1DM professionals to contribute to co-design workshops alongside patients; which was cited as a strength of their research, "having healthcare professionals from both diabetes and ED specialities in one place was useful for bringing together expertise of two fields that do not often have the opportunity to communicate effectively to come up with treatment solutions." (p12). They named the importance of ensuring T1DM was not just consulted within ED/T1DE treatment, but that it was actively embedded into the structure, with ED content in its pure form being found to be not only ineffective but potentially problematic for this group. An example of potential harm was noted by a participant in the use of an ED experimental exercise to observe weight fluctuations over a small period; due to the rehydration effect of insulin reintroduction, this was identified as both highly distressing and counterproductive in T1DE. Three of the six co-design workshops in this research were therefore specifically focussed on diabetes-related content ('insulin titration', 'hypoglycaemia' and 'coming to terms with diabetes'). Their conclusions suggested a need to design new interventions using collaborative knowledges from patients and ED and T1DM professions. Within a service pilot discussed by Partridge et al., (2020) the emphasis on truly co-ordinated multidisciplinary working, rather than an approach of consultation or liaison was prioritised. This was achieved by: specialities delivering aspects of therapy together; by having an overarching psychological approach to T1DM patient health contacts; and with continuous MDT review and oversight. This need to be truly integrative was apparent across the literature, another example came from Hage et al., (2023)'s feedback focus groups from a feasibility trial. Most participants shared that there was not enough emphasis on T1DM even within the adapted ED content, and that it occurred too late on in the programme. Specific feedback included that early sessions had required participants to separate experiences of food and the body from diabetes, which they found impossible. Looking at these papers together shows the importance of bringing working knowledges together in a novel way, rather than simply presenting interventions side by side.

Harrison et al. (2021) produced a Cognitive Behavioural Therapy (CBT) formulation of T1DE and suggested a strength of their model was in bringing a specific T1DM lens to the development of ED that cannot be explained within ED formulations alone. Of note, they did not wholly dismiss ED perspectives and in fact highlighted the shared elements, such as the roles of perfectionism and body image distress. Rather, the model builds upon this foundation, joining it together with T1DM-specific factors. In this sense, the models do not compete against each other, but instead meet in a unique manner. This nicely compliments focus group data in research by Hage et al. (2023) in which a participant suggested that a generic, as well as T1DM-specific, focus was needed because, "we are not just diabetics, we are normal young females living in a society as all others, with all that holds" (p5). Here, it is reminded that whilst interventions benefit from a T1DM lens, they should not be limited by this.

Whilst this literature used varying approaches to treatment, this notion of a joint ED-T1DM approach was consistent across interventions. For example, Dickens et al. (2015) used an intensive inpatient intutative eating approach, whilst Partridge et al. (2020) described a community treatment approach, drawing on use of connection to personal values, utilising validation, and pacing expectations. Despite these differing approaches, both papers emphasised the vital role of multidisciplinary working.

Combining the knowledges and workings of two distinct disciplines may be met with apprehension of barriers in terms of logistical implementation, however, Partridge et al. (2020) provided promising evidence in their pilot intervention of achieving this co-working approach. They shared that, during their service pilot, two distinct specialist teams (ED and T1DM) were able to safely and efficiently deliver holistic intervention to T1DE patients despite working in different locations and using different electronic patient records. This adds to the previously presented ideas of bringing together these distinct knowledges and starts to pave the way for how this can be implemented meaningfully in practice.

Adding further traction to this, Zaremba et al. (2020) conducted focus groups with both ED and T1DE professionals who were reported to repeatedly stress the benefits of working together, learning from each other, communicating clearly, and collaborating on all areas of care. This shows an example of healthcare professionals themselves advocating for, and striving for, a truly joint approach.

2.4.3. Taking a system level approach

Together, the literature highlights the role of the wider system in T1DE intervention, including both targeting the system themselves within intervention, and acknowledging the system for the person within individual approaches.

In the focus groups by Zaremba et al. (2020) healthcare professionals reported the observed impact both from and upon families of T1DE patients, for example, acknowledging the “crazy dynamic”(p1996) that comes with the novel experience of parenting a child with a chronic illness. Hillege et al. (2008) suggest from their case analyses that unsupportive family relationships can leave people feeling “destitute and unsupported”(p175) and proposed patients may then turn their focus to diabetes management to seek value though ‘good results’. Partridge et al. (2020) identified the importance of educating members of the family as part of T1DE intervention, suggesting that increased understanding for the family can be “conductive and enabling”(p130). Family work was also embedded in the inpatient intervention reported by Dickens et al. (2015) in which patients received 2-3 individual sessions per week and family sessions once or twice per month.

Romantic and sexual relationships were also of importance when considering intervention. Hillege et al., (2008) identified that personal relationships with significant partners were disrupted by T1DE, and a lack of understanding of T1DE was often named as the primary cause of this. Participants in the study talked about how romantic partners often became controlling in their approach of trying to help, causing rifts in relationships, and exacerbating psychological distress. One participant talked about the ending of a marital relationship, and another talked about the negative effect upon the sexual element of a relationship due to hypoglycaemia. Conversely, in their exploratory analysis, Coleman & Caswell (2020) relayed how one participant noted that starting a new relationship with a supportive partner was a significant turning point in their ability to manage T1DM and diabulimia. Whilst many of the papers talked about the inclusion of parents within therapy and T1DE intervention, these examples highlight an importance of considering romantic or sexual relationships too.

Hastings et al. (2016) ran focus groups with people recruited from an online Diabulimia support forum. Here, participants reflected upon how being part of a support group had actually influenced discussions with non-group members, such as family and friends. Variability was reported across participants, for some, the group helped to increase their confidence and practice in discussing the topic, which was then generalised beyond the group. For others, it remained challenging to talk outside of the group and these participants kept their interactions about Diabulimia confined to the shared experience group. The authors name this as “selective disclosure” and suggested that this acts as a helpful strategy for people and has benefits for their mental wellbeing. Furthermore, a different participant explained how the group had an indirect effect on other relationships, i.e. in having the protected group space met the need for Diabulimia connection, and therefore Diabulimia became less invasive in other relationships, such as friendships, which could then be protected for socialising and fun. Here, there was no direct intervention with their friends, but there was an indirect improvement to their relationships. This adds an extra layer to the ideas above; whilst the literature highlights the benefits of including the system within intervention, it seems important that this is patient-led, working with the system members that the patient is ready to, and wanting to collaborate with.

Across the literature, more robust education and understanding by healthcare professionals, medical teams and therapists was considered vital for improved T1DE support. This seems particularly important given the life-long nature of T1DM and therefore healthcare teams very much become part of the patient's system. Coleman & Caswell (2020) reported that only 15% of their participants with Diabulimia had indicated having had either positive or mixed experiences with healthcare professions. Within their theme of ‘recovery’ they found that Diabulimia stigma was experienced from professionals which hampered recovery, for example patients being dismissed due to not being “as small as women with anorexia”(p5) and a perceived lack of understanding of T1DM risks in disordered eating. Participants suggested that an array of professionals, including dieticians, psychologists, and nurses all needed further training and guidance to permit effective support. System level approaches to treatment therefore extend not only beyond the patient to their social and familial systems, but to the healthcare system supporting them.

Professionals were highlighted as needing support in working with T1DE relating to their confidence and emotional wellbeing. In focus groups ran by Zaremba et al. (2020), supporting T1DE patients was described as highly emotive for both T1DM and ED professionals. Themes such as being fearful of how to approach T1DE and feeling demoralised were raised and healthcare professionals overwhelmingly reported a sense of being incompetent and insecure in this work. Some professionals disclosed that they had attempted to ignore T1DE related discussions due to not knowing what to do. Here, intervention may need to focus not only upon education and training, but also, as suggested by the authors, on emotional support, supervision, debriefing, and reflective spaces. In this sense, intervention would be conducted indirectly at a professional and healthcare system level.

2.4.4. Cultivating a validating connection

Creating a meaningful and validating connection for those living with T1DE was identified as an imperative for intervention and suggestions of how this could be established varied across the literature. Some papers talked about how this might be developed on a 1:1 basis between patient and healthcare professional; Zaremba et al.(2020) found within their clinician focus groups that "having an open, communicative relationship was the most consistent strategy that allowed diabetes specialists to both diagnose and treat people with T1DE"(p1998). This relationship was reported to involve being patient, paced, and non-judgemental in communication, in addition to practical ideas such as having a consistent clinician. In their guidance for supporting an overarching psychological approach to diabetes care, Partridge et al. (2020) advise teams of ways to create a similar positive and meaningful connection with patients. Some of their pointers include: positioning clinicians alongside the person to share their perspective; validating all emotions; working at an individual pace; celebrating efforts; hoping hope; and believing the person is doing the best they can. Hillege et al. (2008) conclude that professionals who were able to recognise patients as whole people and who attempted to understand the multifaceted nature of patients were perceived as the most supportive. To foster this, professionals were identified to need to set realistic expectations, validate patient struggles, and practice active listening.

Takii et al. (2003) described a slightly different perspective in their inpatient intervention research, in which the therapist took a much more active role in directing the therapy, rather than the 'alongside' role described above. Examples of this was a reported reliance on intense therapist observation and direct involvement of the therapist in the behavioural intervention, taking an approach of instructing and 'coaching' patients, which gradually reduced over the scope of the intervention. However, the researchers did identify an important element of the intervention to be a brief pre-admission counselling intervention which focussed on establishing and building motivation. In this part of the intervention, the therapist was curious of the patient's motivation and led by their wishes, along with gentle encouragement to increase motivation. This may support the idea in the more recent papers and interventions about the importance of a trusting and gentle relationship and the authors conclude this aspect of the therapy was vital to support positive outcomes of the treatment.

A common way in which connection and validation was achieved across the literature was by using groups. Hastings et al. (2016) conducted a thematic analysis with participants who were part of an online Diabulimia support group. One of the reported themes was 'shared identity online promotes recovery' and one subordinate theme identified was 'acceptance and validation of diabulimic community'. Within their findings they showed how participants felt that the group allowed a space in which they were not judged, which allowed a unique form of support that was unavailable elsewhere. This non-judgemental connect is reported to have allowed participants to be honest and open; to share a multitude of emotions; and to receive support and encouragement in a meaningful way. An important aspect of this seemed to be validation and space for all emotions associated with T1DE, as described by one participant, "here I can come and rant and rage, be depressed or proud of myself, feel rubbish or feel great"(p82). It was highlighted that, no matter how hard non-diabetic support networks try, they are limited in how much they are truly able to empathise and understand the experiences of those with T1DE, indicating that group interventions may be particularly valuable for this cohort. This was built upon in several other papers, e.g. a participant in Coleman and Caswell's (2020) research explained "the diabulimia awareness site know exactly how I feel and give unconditional support"(p5) and in their discussion of their group feasibility study, Hage et al. (2023) suggest the most important aspect of the intervention had been "a sense of belonging and not feeling alone"(p7). Facilitation of self-compassion focussed work was found to be beneficial when delivered in group format, with the a sense of shared experience being identified as adding an extra layer of support to the intervention (Boggiss et al., 2020a; Boggiss et al., 2020b). These findings support the use of both online peer support groups, and therapeutic intervention groups when working with T1DE. Importantly, Hastings et al. (2016) report in their findings that online support groups have a potential to pose a threat to recovery, in that interactions at times have a negative impact upon the mood of some members and sometimes placed too much emphasis on T1DM and illness. They therefore conclude that online support groups specifically should not aim to replace relationships within the real world and should be used as a compliment to healthcare intervention, not as a sole means of treatment.

Validation was also linked to acknowledgement of T1DE or Diabulimia as a real problem, and for some the use of a label or name for the difficulties offered this validation. Zaremba et al. (2020) concluded from their healthcare professional focus groups that one of the largest perceived challenges to care of people with T1DE was a lack of diagnostic clarity. A participant within Coleman & Caswell (2020) focus groups shared they had negative experiences with medical professionals and summarised “they just don’t get it, have never heard of it, or don’t understand how stuck you are”(p4). Similarly, a focus group participant from Hastings et al. (2016) shared, “I’ve tried counselling and therapy for EDs but none of them had a clue what Diabulimia was so weren’t much help whatsoever”(p81). These experiences add support to the use of a name, label, or specific education which may allow for further understanding of the problem, in turn increasing validation and connection within intervention.

Largely, themes of validation and connection appeared to offer some respite to feelings of isolation associated with T1DE. Reducing isolation may therefore be a key aspect of T1DE intervention, and may be offered in varying ways, such as via the therapeutic relationship, via group interventions, or via naming and understanding T1DE. Indeed, amongst the conclusions of findings from Hastings et al. (2016) was “this inability to find appropriate support resulted in a strong feeling of isolation among participants” and “while they shared that they had a strong desire for recovery, they felt that this could not be achieved without support from similar others and professionals who were informed about their disorder"(p81).

2.4.5. Promoting self-compassion and acceptance

Approaches to therapy described in the papers were largely dominated by self-compassion (e.g. Boggiss et al., 2020) and Acceptance and Commitment Therapy (e.g. Merwin et al., 2021). Whilst some papers described a formalised approach to this, others described a use of principles associated with these ideas such as identification of personal values amongst other integrative approaches. Overall, these therapeutic approaches were often focussed on supporting empowerment, connecting to a multifaceted identity, and increasing confidence.

Boggiss et al. (2020a; 2020b) outline a series of structured self-compassion exercises which formed part of their T1DE treatment trial which was found to be acceptable and feasible for implementation. Such tasks included teaching of skills such as comforting gestures, kindness meditation, and a group common humanity exercise. 13 of 15 participant feedback responses reported that they had increased coping resources post-intervention which suggests this approach may give people useable and tangible skills and strategies, an area identified as lacking as noted at the start of this review. Other papers took a more integrative approach, but elements of self-compassion were apparent. For example, Harrison et al. (2021) developed a Cognitive Behavioural Therapy (CBT) formulation specific to T1DE, within this, there were themes of self-compassion such as having a 'good enough' view of T1DM and adaptive and balanced view of self-management fluctuations. Partridge et al. (2020) listed the key components of psychological intervention from their service pilot; within this was developing compassion for the self, which was listed alongside other elements such as: psychoeducation; increasing self-efficacy; cognitive restructuring; and relapse prevention.

Principles of ACT were prominent within the literature, most notably there were references to supporting people with T1DE to accept T1DM within their lives and work towards a life in which they could connect to their values and live alongside T1DM. Merwin et al. (2021) took a structured ACT approach in their trial of an iACT (app-based ACT) for T1DE, which they concluded "holds promise"(p11) in treating T1DE .

These two approaches seemed from the literature to be complimentary in nature rather than distinct, for example, Merwin et al. (2021) discussed how the acceptance intervention as part of the iACT trial focussed on increasing compassion and reducing self-punishment for users. Likewise, in their discussion of the self-compassion trial, Boggiss et al. (2020a; 2020b), suggested that the self-compassionate approach supported the participants to be less self-critical and therefore more accepting of the impact of T1DM. The use of both self-compassion and acceptance appear useful in T1DE intervention, whether this may be a structured approach such as ACT, or as a principle underlying an integrative therapeutic approach.

2.4.6. Learning from combining the literature

Returning to the SLR question, I have constructed an understanding of the current interventions and service provision for T1DE which is outlined in the categories above. Whilst the literature is sparse and clinical tools are limited, I have understood that current treatment is working towards: combining ED and T1DM knowledges; working with varying levels of the system; aiming for connection and validation; and aiding development of self-compassion and acceptance. Bringing the literature together has allowed me to gain novel insights and connections that would not be possible through looking at the papers in isolation. Some of the key ways I have understood the cross-literature links include:

- Balancing the role of T1DM within ED specific care. The need for T1DM to be central within disordered eating approaches was strong and there was a shared message of conventional ED treatments being ineffective. However, some research noted that people exist beyond T1DM and there are risks of limiting people and support if T1DM is over-emphasised.

- Being person-centred with system involvement. Whilst encouraging findings are shown from active inclusion of the family and social circles within treatment, this might not always be warranted or needed. Some research indicated that indirect effects from having a validating group membership was enough to positively influence their social relationships within need for direct intervention.
- Whilst establishing validation and making meaningful connections was identified as important, the review highlighted the varying forms that this can take in implementation. Some of the literature draws on the use of groups, whilst other papers look to the therapeutic relationship with clinicians, or the importance of an agreed and understood label for experiences (e.g. T1DE, diabulimia).
- Individual therapy work varied in implementation across the literature but was often underpinned by principles of both self-compassion and acceptance, with an aim to learn how to live alongside T1DM.

2.5. Gaps in the literature

Whilst drawing attention to the cognitive, behavioural, emotional, and systemic factors active within T1DE, the role of understanding the physical body, and in particular the psychological perception of the body and its role within the world is lacking within the literature. This was apparent particularly when considered alongside the ideas presented in the introduction chapter of this thesis, in which T1DM was suggested to have numerous physical and bodily interactions.

In their case analyses, Hillege et al. (2008) did identify ‘the physical dimension’ which was one factor identified alongside 3 others (an emotional dimension, a social dimension, and personal relationships). The authors identified this physical dimension as “all the physical work” relating to the physical self; this draws attention to the potential role of the physical body within T1DE. The authors keep a relatively practical view of this, referring to discussions such as blood glucose readings and injecting of insulin, but they do offer a suggestion that it is an “intrapsychic process, which leads into the emotional dimension of the person”(p172). Zaremba et al., (2022) also drew attention to the role of the physical body within their co-design workshops in which a sub-theme of ‘relationship to body image’ was identified. Within this subtheme, there were some suggestions of the role of the physical body, such as a participant sharing “your body is betraying you, it’s doing something it’s not supposed to”(p9), and the authors considered how this interplayed with the idea of self-worth and body image.

This starts to draw links between the physical and psychological experiences of people, but a gap remained in the exploration of peoples’ understandings of their physical bodies and their perception of their bodies within the world, T1DE, and wider identity.

2.6. Rationale for the current research

I aim to support this small but growing literature to better understand T1DE experiences; specifically taking a focus on the perceived role of the body and the way in which people with T1DE come to understand their physical body as part of their whole selves and their social contexts. This focus is a unique aim, building on the existing literature reviewed above which has started to consider the emotional, behavioural, cognitive, and systemic patterns of T1DE. Whilst the research is positioned towards the physical body, the literature has indicated an important dynamic between the physical and the psychological and so the current research aims to see these processes as interlinking and holistic, rather than separate. Interest is therefore directed towards how the body is understood, the links made with cognitions and assumptions, and the social nature of bodily experiences.

The research question posed is: *“How do people with lived experience of T1DE understand and perceive the role of their physical bodies and experiences?”.*

3.0. Methodology

3.1 Chapter overview

This chapter details the rationale for choosing a Constructivist Grounded Theory (GT) framework and how I arrived at my design decisions. I will outline the processes of recruitment, inclusion criteria, data collection and data analysis. I will also include my reflections on the processes and the methodological choices that I made. I will detail the ethical considerations addressed and state the application for ethical approval. The role of lived experience consultation within the project will be described along with the steps I took to be reflective, and to try to observe the data in varying ways, with awareness of my own lens and interpretation. The chapter will be concluded with a quality evaluation of the research against qualitative research criteria.

3.2 Revisiting epistemology

As detailed in section 1.3.1., I held a moderate constructionist epistemological stance (Harper, 2011) and so was interested in adopting a framework which would support my understanding of how knowledges are created within the social world and situated in context. Whilst the critical realist ontology underlying the stance adopts a belief of a pre-existing reality to T1DM, the moderate social constructionist epistemology holds the view that it would be impossible for research to provide a untouched view of this. Instead, I was curious about exploring the ways in which I could construct meaning from how people experience T1DE within their systems and contexts. It was important to me to choose an approach which would acknowledge and utilise the positioning of participants in telling their stories and myself as the researcher in hearing and interpreting the stories.

3.3. Design

3.3.1. Choosing Grounded Theory

As identified in previous chapters, T1DE is an area which is poorly understood and newly developing, both clinically and within academic research. When an area is under-researched or has little existing evidence base, GT offers an approach with both structure and flexibility to allow exploration of a novel field (Chun Tie et al., 2019). GT was a good fit for my epistemological position within the research topic as it seeks to create theories that are ‘grounded’ in data gathered and utilise a bottom-up approach (Glaser & Strauss, 1967). This approach therefore offers an alternative to researching pre-existing theories and hypotheses; instead opening opportunity for new theories within context (Willig, 2013). These theories are recognised to be specific to the context from which they were developed.

I was aiming to capture rich data from participants to guide me in forming an in-depth understanding of their experiences, how these have been constructed, and how they interact with the social world. It was therefore important to me to choose a qualitative and explorative approach to the research. Taking a qualitative approach also supported my wish to step away from the idea, defined by Haraway (1988) as “the God’s eye view” in which researchers are encouraged to detach from the research topic or strive for neutral and controlled circumstances for data collection. I instead recognised my role within the research and preferred to immerse myself into the data, along with recognising the contextual factors which I sought to be curious, rather than avoidant of.

GT was favoured over other options due to its fit for both the research topic and epistemological positioning of the research. An Interpretative Phenomenological Analysis (IPA) approach (Larkin et al., 2021) would also have given a rich insight into peoples’ lived experiences which I was seeking, however, this approach would have explored the experiences of a small homogenous sample. I was less interested in looking at a small and specific sub-section of T1DE, for example, diabulimia, and instead was interested to hear from a heterogeneous group of people falling under the umbrella of T1DE, for example, I wanted to hear from people who had experienced insulin restriction, but also people who had experienced different forms of disordered eating, such as binge eating or food restriction. I had also considered using thematic analysis (Braun & Clarke, 2006) which would have allowed a more heterogeneous sample than IPA, gaining a broader, less individually in-depth account, however, I felt that this would not capture the social and contextual links and processes that would support development of a theoretical understanding of T1DE. Narrative analysis has been considered as a useful way to explore experiences relating to health and health psychology (Stephens, 2011). Whilst this approach would have met my desire to account for context, discourse, and positioning, I feel this may have limited the ability to capture wider social processes beyond language and communication.

GT therefore became my preferred approach, which allowed me to take an explorative approach to a heterogeneous group of people experiencing variations of T1DE, with an aim to draw together the experiences into a theoretical understanding. This unique feature of theory building was appealing to support my aims of constructing and understanding social processes and viewing human experiences as dynamic and layered. I was attracted to the options of purposeful sampling within GT which would allow me to change or direct recruitment as per data analysis (Charmaz, 2014). As I was hoping to speak to a range of participants and as I had little existing hypotheses related to expectations of direction of this research, it was important to use a framework which would allow such flexibility during data collection and analysis.

3.3.2. Choosing Constructivist GT

GT was introduced by Glaser & Strauss (1967), taking a somewhat positivist epistemology in that they spoke of discovering theories and the emergence of categories. This way of viewing the GT approach would position the researcher as looking to uncover a reality awaiting to be discovered. It also suggests the researcher themselves would have minimal involvement in the development of the theory, but rather they would deliver a formed theory once uncovered. (Willig, 2013).

This positioning did not align with my epistemological stance and therefore I looked to recent variations of GT which have stepped away from this positivist position. Instead, I adopted a Constructivist GT variation which considers research as a construction that occurs under specific contextual circumstances (Charmaz, 2014). This approach sees the researcher as actively embedded within the research and so allowed me to observe and interpret, rather than ignore, my positions and conceptualisations relating to the topic.

Taking this approach has meant that I have wanted to continually take steps to consider my own position within the research and examine my interpretations. Charmaz outlines the importance of memo-writing during analysis to actively engage with the data and describes this as “conversing with yourself about your data” (Charmaz, 2014, p162). I have utilised memo-writing during analysis along with the use of a reflective journal and frequent supervision to bring awareness to my own influence on the development of the data and theory. Specifically, I have been aware of how my clinical working experience with physical health and T1DM may have guided my interest and perspective with the data. One example of this was that I have previously delivered consultation and training to medical teams working with people with Type 1 and Type 2 DM in a general hospital regarding communication about regime adherence. I therefore may be particularly drawn to ideas about diabetic non-adherence, and I also hold the assumption that diabetes and diabetic treatment is a psychologically difficult and distressing adjustment.

As outlined in section 2.2. I chose to engage in a literature review despite the disputed role of this in GT research. Constructivist GT does not recommend this disputed avoidance of a literature review but instead suggests that the literature should be reviewed to avoid research repetition and to establish rationale; but that the literature should be thought of as fallible in nature, rather than ‘true’ (Charmaz & Thornberg, 2021; Thornberg 2012).

3.3.3. Choosing interviews

GT allows a multitude of methods to gather data including one-to-one interviews, focus groups, observations, and written prose (Charmaz, 2014). I was immediately drawn to speaking to participants directly and was keen to use either interviews or focus groups. Willig (2013) describes that interviews allow the researcher the opportunity to ask participants directly about a particular aspect of their life and describes the researcher to ‘trigger’ participant talk. Hiller & DiLuzio (2004) found that qualitative interviews offer a chance for complex experiences to be refined and organised via the process of the interview, allowing the researcher insight into the studied phenomenon. This was particularly relevant, as I was keen to understand *how* participants understood their experiences.

Focus groups were considered as they have been identified as a useful way of gathering data relating to health and illness (Wilkinson, 1998). However, I had apprehensions about using this method due to my aim to hear from a heterogeneous sample and I worried that a group may not offer enough space for all participants with differing experiences to share meaningfully.

3.3.4. Lived experience consultation

Lived experience consultation has been embedded in the research from the stage of proposal and is ongoing with plans to support dissemination. Consultants have included people with experience of T1DE and T1DM, either directly or indirectly via loved ones. I sought specific guidance in advice to support participants to have a positive experience of involvement, and also how to best share research materials and findings with target communities. Examples of notable contributions included support with the wording of interview questions; considerations of the interview setting to avoid replicating difficult clinic-based experiences; consideration of language used; and the decision for the project to consider the umbrella experiences of T1DE, rather use of the term ‘diabulimia’.

The support from consultants has been invaluable and has made me aware of the everyday biases and T1DM stigma in existence. They have aided my reflection, decision making, and have opened up perspectives to me, particularly as I sit as an outsider researcher to T1DE.

3.4. Ethics

3.4.1. Ethical approval

Ethical approval was granted by the University of Hertfordshire’s Health, Science, Engineering & Technology Ethics Committee (protocol number LMS/PGR/UH/05294) and the Health and Social Care Research Ethics Committee (protocol number LMS/PGT/NHS/02988) (Appendix C). The research was conducted consistent with guidance from the British Psychology Society (BPS) Code of Human Research Ethics (2014).

3.4.2. Ethical considerations

3.4.2.1. Informed consent

In line with the BPS guidelines (BPS, 2014), information relating to the study aims, rationale, content, and potential risks and benefits was given to all participants ahead of their participation in the form of a Participant Information Sheet (Appendix D). All participants were offered the opportunity to discuss any questions ahead of the interview via either email, telephone or video call and they were offered this again immediately prior to the interview. It was explained to participants both before and after the interview of their right to withdraw their consent or data for up to two weeks after the start of the interview, after which their data would be analysed and unable to be removed.

For participants recruited via NHS services, it was clarified that participation was not in any way linked to their clinical care.

3.4.2.1. Confidentiality

Interview recordings were accessible only to myself and were stored on my secure university OneDrive. I transcribed all interviews personally and deleted the recordings following this process. During transcription, identifiable information was removed. This included reference to specific names, hospitals, and relatives’ names, but also included minor changes to details which may lead someone to be identified, e.g., specific details of other diagnoses or life events which were described in specific detail. Participants recruited from NHS services were reminded that their participation in the project would not be shared with their care team.

Consent forms and demographic information were stored in a separate folder to the transcripts and were password protected. These will be destroyed upon my completion of my doctorate programme.

All participants have been given pseudonyms within the write up and these pseudonyms will be used in any other publication or dissemination.

3.4.2.3. Potential distress

It was possible that distress could be aroused by the interviews. I devised a distress protocol which was reviewed by the local ED team and a de-brief sheet was given to all participants with signposts to support (Appendix F-G).

Care was taken in the research design to reduce the likelihood of distress. Charmaz & Belgrave (2012) suggest that carefully considered interviews can present an opportunity for participants to have space and connection in which comforting meaning can be formed for them.

Charmaz (2014) guides on how to ensure questions are worded to avoid eliciting distress, e.g. inviting the participant to be in control, “can I ask you about…?”. Interviews were designed to be participant-led and non-pressuring.

On balance, whilst framing questions in a sensitive way, I also felt it was important to allow space for participants to discuss difficult experience. Guidance suggests that researchers should not shy away from difficult subjects as acknowledgement of the difficulties can be validating for participants, normalising distress from painful experiences (Melville & Hincks, 2016; Owens, 2006).

All participants were asked to remain after the end of the interview for a brief check-in as a minimum, and were offered an optional de-brief space of 30 minutes.

3.5. Participants

3.5.1. Sampling and recruitment

Initial recruitment was aimed at any people with direct lived experiences of T1DE (as defined in section 1.5.2.). Participants were recruited via advertisement in:

- Local NHS diabetes clinics
- Local NHS community ED services
- Social media
- Diabetes charities

I approached an ED charity but due to their reduced capacity was unable to recruit with them. The recruitment of participants via routes more typically associated with T1DM rather than EDs may have impacted the presentation of participants that came forward. I attempted to reach the ED population by recruiting in ED NHS clinics and by using ED related hashtags on social media. A small number of participants were recruited, but overall recruitment came heavily from T1DM communities (15 of 17 participants).

McCrae & Purssell (2016) emphasise the importance of theoretical sampling in GT; this is the process of making active decisions about who and where to recruit following initial data collection and analysis. Ways I engaged in this were by specific attempts to recruit men, following my first interview with a male participant in which I took a different understanding from his experiences than the other participants (all female) and was able to recruit a further two male participants. I noticed a gap in my understanding of binge eating and pursued theoretical sampling here also, obtaining three further participants with binge eating behaviours.

GT does not specify a precise number of participants for recruitment and instead observes for data saturation, in which no new conceptual information is obtained from new participants which add something novel to the developing theory (Robinson, 2016). Dey (1999; 2007), argues that data collection will always struggle to be exhaustive and may never in reality be achieved. Willig (2013) instead suggests that whilst researchers should *aim* to reach saturation, this may be an idealistic, rather than achievable, aim arguing that different perspectives and constructions will always be possible in GT enquiry. I therefore did not aim for a set number of participants, but rather aimed to develop a theory which was grounded in data sufficient enough to account for information provided by further participants.

A total of 17 participants were recruited; I started discussions with my supervisor regarding potential sufficiency at around participant 11. Whilst my categories were enriched with examples and support, I did not construct further new categories and processes from the next four participants and no novel or surprising understandings were formed from these. I therefore considered the criteria for stopping further recruitment to have been met at participant 15.

3.5.2. Member reflecting

I interviewed two final participants who were asked to share their experiences alongside the constructed categories and theoretical model. I used the guidance of Tracey (2010) to position these participants as ‘member reflecting’; a position differing to ‘member checking’ or ‘member validating’. In member reflecting, the participants are not checking that the research is ‘correct’ or establishing a truth to the model, but rather, deepening and enriching the model whilst sharing their experiences.

Both participants described that their experiences fit well with the draft model and therefore, in agreement with the supervisory team, we considered there to be sufficient data to end recruitment. These participants had varying experiences which added to my confidence that data sufficiency had been reasonably met; i.e. one was diagnosed with T1DM in childhood and the other in adulthood, one mainly experienced binge eating and one mainly experienced food and insulin restriction.

3.5.4. Inclusion and exclusion

I included a broad scope of disordered eating experiences within the inclusion criteria, as per the T1DE umbrella previously defined. I felt I could best capture this population by having a flexible criterion for inclusion and welcoming people with or without formal ED diagnoses. As there has also been slightly more focus on intentional insulin restriction within T1DE, I specified within recruitment posters that people with and without these experiences would be eligible. Full inclusion and exclusion criteria can be found in Table 7, and the recruitment poster can be found in Appendix J.

Table 7

Inclusion and exclusion criteria

Inclusion criteria
• Aged 16+ • Lives in the UK • Has a diagnosis of T1DM • Has experience of disordered eating (formal ED diagnosis, or undiagnosed disordered eating) that has occurred <u>concurrently</u> with T1DM • May include mismanagement of diabetes medication, e.g. insulin restriction (although not required) • Disordered eating may have had its onset either before or after the T1DM diagnosis

Exclusion criteria
• Has Type 2 diabetes • Acutely unwell or experiencing acute diabetes related complications (e.g. currently in hospital, receiving emergency or urgent care) • Lacks the mental capacity to consent to participation • Has experienced disordered eating non-concurrently with diabetes (e.g. disordered eating prior to T1DM diagnosis, and has not had any further disordered eating since being diagnosed with T1DM)

3.5.4. Sample characteristics

Participant demographics are presented in Table 8 and summarised in Table 9. Participants with two numbers in the final column of 8 reported having had two distinct experiences with disordered eating or ED. Age brackets have been used in place of specific age to protect anonymity.

Table 8

Participant demographics

Pseudo-nym	**Current age**	**Gender**	**Ethnicity**	**Formal Eating Disorder diagnosis (Y/N)**	**Presenting disordered eating**	**Age of T1DM diagnosis**	**Duration of T1DM diagnosis (years)**	**Disordered eating onset in relation to T1DM diagnosis (years)**
Jessica	26-30	Female	White British	Yes	Diabulimia	21-25	6-10	0
Owen	51-56	Male	White British	Yes	Binge Eating Disorder	11-15	41-45	+36
Louise	36-40	Female	White British	Yes	Binge Eating Disorder	26-30	6-10	-7 +8
Bianca	31-35	Female	White European	No	T1DE	21-25	6-10	+1
Ellie	31-35	Female	White British	No	TIDE	0-5	31-35	+10
Charlotte	36-40	Female	White British	No	Restrictive eating	36-40	0-5	-22 0
Jo	21-25	Non-Binary	White British	Yes	Anorexia, food restriction, insulin omission	6-10	16-20	+5
Bec	51-56	Female	White British	No	Insulin restriction	0-5	46-50	+12
Ava	21-25	Female	Iranian	Yes	Diabulimia	11-15	11-15	+5
Jada	26-30	Female	Black African	Yes	Diabulimia	16-20	6-10	+2

Robyn	21-25	Female	White British	Yes	Anorexia and Diabulimia	6-10	11-15	+8
Ivy	21-25	Female	White British	No	Insulin restriction, regime mismanagement	6-10	16-20	+7
Summer	21-25	Female	White British	Yes	Binge Eating Disorder	11-15	11-15	+1
Mark	51-55	Male	White British	No	T1DE	0-5	46-50	+14
James	26-30	Male	White British	No	Bulimia-like symptoms (vomiting, purging)	16-20	6-10	0
Shauna	21-25	Female	White British	No	Restrictive eating	11-15	6-10	+8
Alice	26-30	Female	White British	No	Purging and insulin restriction/ avoidance	21-25	6-10	-5 +1

Table 9

Demographic summaries

Mean age at time of interview (range)	*32.5 (21 – 54) years*
Mean age of T1MD diagnosis (range)	*17.9 (2 – 48) years*
Mean onset of disordered eating in relation to T1DM	*+6.9 years*
Ratio of gender	*3M/ 13F/ 1N-B*
Ratio of formal ED diagnosis	*8Y/9N*

3.6. Data collection

3.6.1. Interview format

Local participants were offered face-to-face or virtual interviews and geographically distant participants were offered virtual interviews; all opted for online. Interviews lasted between 40 – 70 minutes which was led by how much time participants spent telling their stories and responding to questions. All participants were asked to stay for at least a short 5 minute debrief after the interview and were invited to use the space for up to 30 minutes if they wished. Participants were advised that they could turn their camera off for the interview if they wished, one participant took this option.

3.6.2. Interview pack

As GT aims to develop 'bottom-up' theories, strict or standardised interview schedules are not typically used (Foley et al., 2021). GT aims to elicit genuine feelings and understandings from participants perspective and for the participant to be guiding within the interview direction and theory creation. I therefore avoided a heavily pre-determined approach to interviews which are seen in other methodologies, such as phenomenological approaches (Wimpenny & Gass, 2000). Instead, I devised an 'interview pack' in which I established broad, semi-structured questions to guide my interviews in a loose and flexible way. The pack was used to select relevant questions or directions per participant and was not followed in a rigid or ordered way.

Earlier interviews had broader and fewer questions from the pack, and as theoretical sampling and recruitment continued, questions became more focussed. In her guidance, Charmaz (2014) advises "your first question might suffice for the whole interview if stories tumble out". This did happen with one of my early participants, who spoke through their journey with T1DE and the sense making they had made from their experiences for around 50 minutes following the question *"Can you tell me about your experiences with T1DE?".* As per Charmaz's advice, I avoided interrupting participants to move onto new questions and instead took a listening approach, using brief verbal and non-verbal encouragements (Charmaz, 2014).

The final two interviews had a different format in that participants were asked to look at the draft theoretical model and draft categories that I had started to construct. They were asked to share their experiences with T1DE alongside these ideas and were asked to consider whether the categories did or did not fit with their understandings and experiences. They were asked to share any ideas or understandings that were not captured within the constructed categories.

3.6.3. Reflexivity during interviewing

Tools designed to assess the methodological rigour of qualitative research highlight the importance of being reflexive, sincere, and aware that the research is seen from the perspective of the researcher (Elliot et al, 1999; Tracey, 2010). Birks et al. (2019) warn that GT researchers need to be aware of any biases which may impact the research; they suggest that whilst it is impossible to be neutral of biases, biases should not mistaken for theoretical sensitivity (the identification and extraction of key data to support an emerging theory).

Taking steps towards recognising this, I took memos and notes directly after all interviews to consider my initial perceptions and thoughts. I looked for key recurring ideas that I was noting and compared these to early notes from during the proposal stage of the project. I chose to transcribe all interviews myself to closely revisit the interviews and I used this opportunity to pause and check my biases whilst listening to the recordings. I made notes of the things that surprised me in the transcripts, such as the things that I had not remembered from that specific participant, or that I had not included in my memo notes. An example of this was my assumption of a negative physiological experience of injecting insulin. My working experiences may have informed this, and I noticed that I made substantial notes when participants did speak about this but was surprised to find this was disproportionate to the analysed data, in which few participants actually identified this. I therefore considered whether I was potentially amplifying the prominence of this within the data when I heard it due to my previous knowledges.

3.7. Data analysis

I transcribed the interviews verbatim and analysed the data using a combination of NVivo 12 Software and 'pen and paper' analysis. All interview transcripts were uploaded to NVivo and coded using the software. I used flipchart paper and post-it notes to manually consider how codes started to connect as this allowed me more freedom of movement. Alongside this, I worked with NVivo to pull the quotations that I had coded and reviewed and revised the codes that I had created.

3.7.1. Coding and categorising

I started with line-by-line coding of the first six interviews as per guidance (Charmaz, 2014) (Appendix J). This allowed me to connect intimately with the data and stretched my thinking beyond my initial thoughts. It forced me to look more closely at sentences that I may have overlooked and prompted me to really absorb what participants had told me. Coding at this stage remained relatively close to the spoken word of participants. I used gerunds in my coding process, as suggested by Charmaz, in which codes are named using action terms which typically end in '-ing'; Charmaz advises that this pushes the researcher away from viewing data as static topics and sets the foundation for sequenced connections. I noticed that at times this was difficult to achieve, and it slowed my coding process, although opened my thinking beyond the spoken word. For example, I initially looked at a line of data and thought of the code *'a perk of diabetes'*; upon further reflection and aim to use gerunds, this code was renamed as *'finding a benefit of diabetes'*. This allowed me to see the data in a different way, and aided connection with other codes.

Initial codes were gathered into focussed codes for the next stage of analysis and reviewed these actively with supervisors. We discussed how and why I had grouped codes together and actively started to look for differing interpretations together. I then moved into focussed coding, in which prominent codes I had perceived to emerge from the data were built upon and developed. I made sure to remain open to novel codes and ideas and reflected using my journal when codes and concepts were not clear upon their ‘fit’. As per the guidance of constant comparison, I regularly moved between transcripts, codes, and early categorisation to develop ideas critically.

Whilst doing this, I started to build ideas of social processes in which categories of the data connected together conceptually. At this stage, category names were moving away from the specifics of the spoken word and were indicative of my construction of the data.

3.7.3. Theory building

I used pen and paper to start connecting my categories and ideas together, which allowed me to visualise and move concepts around flexibly, aiding process identification. As advised by Charmaz (2014) I used diagramming to consider how the categories were related and this allowed me to be succinct with data representation. I made several drafts of theoretical diagrams, which varied and developed from flow-chart style linear processes, to more circular and overlapping ideas of category relationships (Appendix K). Theory drafts were consulted on with supervisors, lived experience consultants, and member reflecting participants to enrich perspective.

3.8. Quality appraisal

Charmaz & Thornberg (2021) provide guidance which they suggest can be used in the form of a quality checklist in conducting constructivist GT research. They forewarn (supported by Barbour, 2001) that prescriptively adhering to checklists can be counterproductive if it hampers authentic engagement with the method and data. I therefore used their checklist as a guide whilst analysing but held suggestions flexibly to avoid being restricted.

Table 10

Quality appraisal of the research (Charmaz & Thornberg, 2021)

Guideline	**Adhered to?**	**Comments**
Be methodologically self-conscious	Yes	I have outlined my epistemological stance and rationale for the research.
Learn about the inquiry	Yes	Primary supervisor of the project has completed their own GT research.
Have a non-committal approach to existing literature	Yes	A literature review was completed but held tentatively.
Gather rich data	Yes	I structured the interviews to be open and participant led. Interviews lasted up to 70 minutes and aimed for participants to tell their stories in detail.
Be transparent	Yes	The steps taken to conduct the study are outlined in detail in this chapter.
Go back between data and analysis	Yes	I engaged in constant comparison as per the GT process.
Tolerate ambiguity	Yes	As evidenced in my reflective journal accounts, I experienced a lot of ambiguity and aimed to allow and explore this.
Ask progressively focussed questions	Yes	As outlined, I used an interview pack to guide my interviews and questions became more focused within later interviews.
Play with theoretical explanations	Yes	I engaged in several stages of theory development, drafting and redrafting ideas and

		playing with different ways of visually presenting the categories.
Collect sufficient data	Yes	In line with data sufficiency, I noted that no new or novel ideas were added following the final interviews that I conducted. I asked the final 2 participants to share experiences in the context of checking the draft theory and whilst the data enriched the model, it did not identify any novel concepts that did not fit within existing categories.
Question categories	Yes	In research supervision I queried categories and sub-categories and how they were represented. I also used reflective journal entries to support this as well as engaging in peer review of categories.
Treat codes, categories, and theory as provisional	Yes	Codes, categories and theoretical development were continually held tentatively. I used peer spaces, supervision and self-reflection to develop these and many of my categories were re-named several times.
Compare analysis to the existing literature	Yes	To be presented in discussion chapter.

Following completion of analysis and write up, I reviewed the research using Elliott et al. (1999) guidelines for publication of qualitative research which is presented in Table 11.

Table 11

Quality appraisal of the research (Elliott et al., 1999)

Guideline	Adhered to?	Comments
Owning one's perspective	Yes	I have outlined my epistemological stance and my experiences with the research topic prior to the research in earlier chapters. I have also provided entries from reflective journals.
Situating the sample	Yes	Participants' contexts are reported.
Grounding in examples	Yes	Quotes and examples have been provided within the write up.
Providing credibility checks	Yes	The final 2 participants checked the theoretical model draft and shared experiences in the context of the theory. Lived experience consultants, supervisors, and peers checked and commented upon the theoretical model.
Coherence	Yes	I have presented the information in both narrative prose and via diagrammatic representations. I have provided a breakdown of each process that I noticed as well as an in-depth break down of each category and subcategory.
Accomplishing general or specific research tasks	Yes (general)	The research aimed to provide a general understanding of the phenomenon of T1DE and did so by capturing a range of participants (e.g.

		those with restrictive eating, insulin restriction, binge eating, etc).
Resonating with readers	Yes	The research has been reviewed by supervisors and lived experience consultants.

3.9. Dissemination plans

Dissemination plans are being discussed in collaboration with lived experience consultants. The research will be presented at a Diabulimia Helpline Conference later this year (Appendix I).

4.0. Results

4.1. Chapter overview

This chapter presents the constructed GT theoretical understanding of the processes underlying how people with T1DE make sense of the experience of their body within their identity and social world. The theoretical understanding is displayed by visual diagramming and concept summarisation. Each developed process is then described and illustrated by participant quotes, broken down into categories and subcategories.

4.2. The GT model and overview

Figure 2 provides a visual representation of the proposed theoretical understanding of how T1DE participants made sense of the role of their body and physiological experiences. Four main processes were constructed from the data which are not numbered as they are thought to act in a circular, rather than linear, nature. Processes were constructed from 8 categories and 10 subcategories which are displayed in Table 12 followed by a description of each, illustrared with participant quotations.

Figure 2

Diagrammatic representation of the GT theoretical understanding

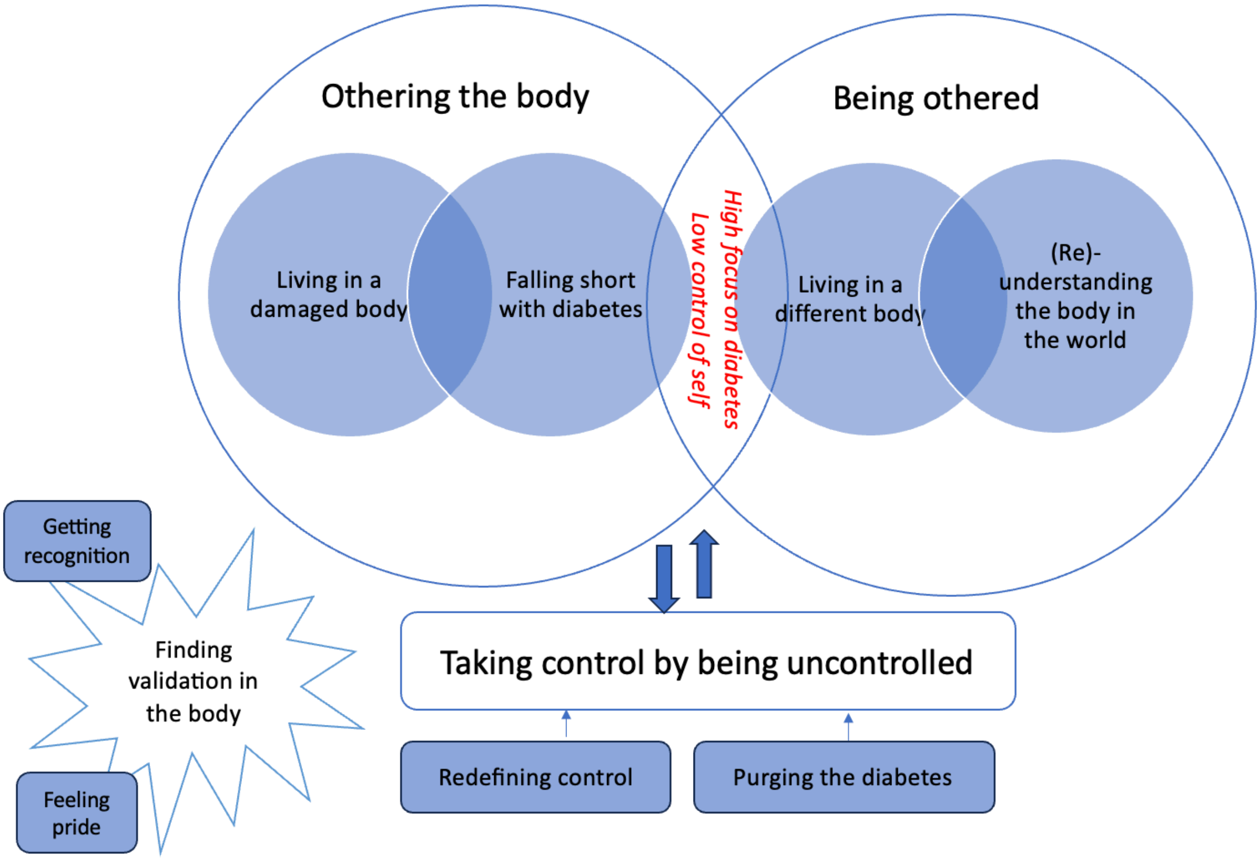


Table 12

Processes, categories and sub-categories forming the GT model

Process	Category	Sub-category
Othering the body	Living in a damaged body	Being let down by the body
		Becoming your own clinician
	Falling short with diabetes	Living in shame
		Striving for an impossible perfection
Being othered	Living in a different body	Standing out
		Minimising and magnifying diabetes
	(Re)understanding the body in the world	Methodicalising the role of food
		Losing self because of diabetes
Taking control by being uncontrolled	Re-defining control	Outsmarting everyone
		Using a secret superpower
	Purging the diabetes	
Finding worth and validation in the body	Getting recognition for the body	
	Feeling pride in the body	

4.3. Process: Othering the body

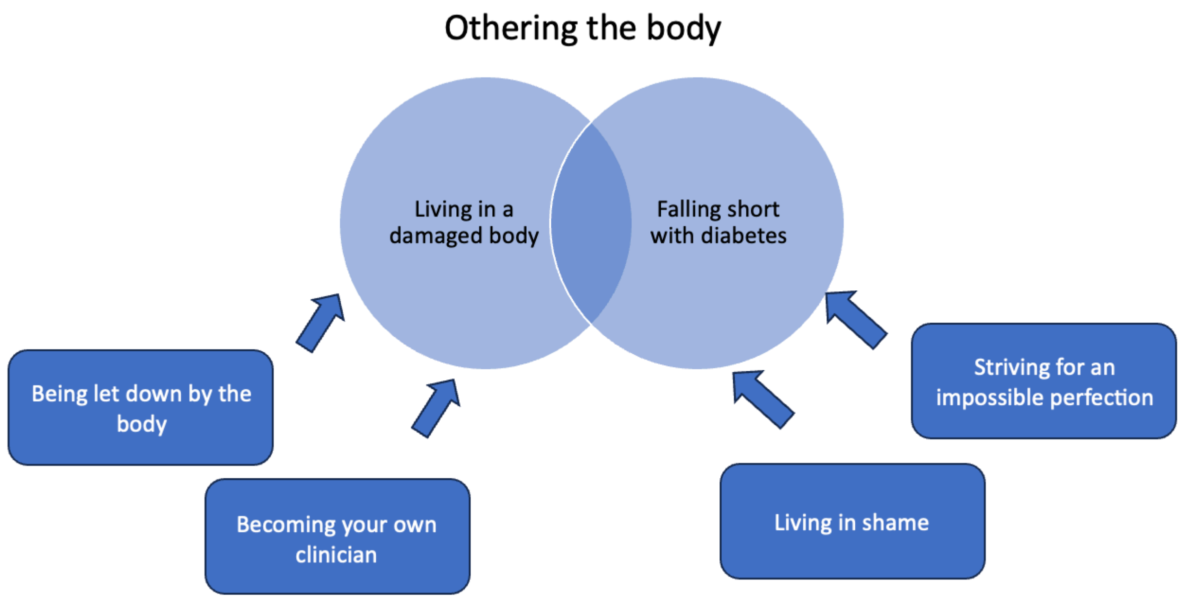
> *"I think often like, there's like a mismatch, especially with the diabetes, like a mismatch of how the body feels and how the brain feels"* (Charlotte).

This process *‘othering the body’* captured the way I understood participants to have engaged in a distancing or ‘othering’ of their physical bodies when making sense of this commonly reported disconnect articulated by Charlotte. Like Charlotte, many participants seemed to grapple with a separation between the physical body and the perceived self, mind, and brain. At first, this appeared to be a passively observed experience, but as I heard more, the picture developed to be more active in nature, driven by factors such as shame and pressure. For some, this seemed a conscious or even intentional separation, whilst others seemed to feel pushed unknowingly into this distancing with their bodies. Importantly, the othering of the body appeared to be intrinsically linked to othering a *diabetic* body.

I formed this process by the seemingly overlapping nature of two significant categories: ‘living in a damaged body’ and ‘falling short with diabetes’ (both formed of two sub-categories, elaborated upon below). This relationship was between the experiences of physically existing within the limits of a diabetic body and the feelings of failure associated with the pressures of self-management to simply stay alive. These concepts seemed to come together, resulting in participants feeling they were passively existing in a damaged body. Despite working hard to care for, and look after this body, participants spoke of how they often burnt out or tired of this constant pressure and, either consciously or subconsciously, separated or distanced their physical body from themselves and their identity. A diagrammatic representation of this process is shown in Figure 3.

Figure 3

Process: Othering the body



4.3.1. Category: Living in a damaged body

Participants spoke of the physical impact of living in a diabetic body and their awareness of the condition as life-long with indefinite impact on their physical bodies. Participants described their bodies as being broken, failing and damaged in some way and some reflected upon the injustice of this as they had worked hard to take care of themselves. Many talked of the shock at diagnosis and a disbelief that this could happen to them, which was particularly notable for participants diagnosed in adulthood.

This category relates to how participants experienced T1DM and the impact upon their lives and interactions. It was notable that participants diagnosed in adulthood often referred to the time of diagnosis as a crushing moment of shock and significant change to their lives. Participants diagnosed in childhood often identified specific moments in time in which T1DM took a stronger hold of their life, this usually reflected a period of increased independence, for example some participants spoke about a change when they went to secondary school, and others spoke of moving away to university. At these times, this feeling of the body being damaged seemed particularly strong and seemed to reflect the contextual nature of changes in independence or social circles.

The sub-categories below describe how participants felt limited by living in a diabetic body; struggled with self-management; and felt emotionally drained by T1DM.

In her member-reflecting interview, Shauna reflected upon how she had felt almost protected from this experience, attributing this to her early acceptance of T1DM, suggesting T1DM acceptance could have played a protective role in how she interpreted T1DM to have impacted her body.

> *"I've spoke with friends like or other women who have diabetes, and it's weird, we have different perceptions of it, they would align to like the damaged body feelings and like kind of anger or frustration about the situation. And I don't know if that's my perspective, as I've never felt anger or upset about it and I don't really dwell on it. Because I think I just, I was old enough to just know and accept at the time like this was… this was it. Nothing you can do."* (Shauna, member-reflecting).

4.3.1.1. Sub-category: Being let down by the body

Participants described a sense of helplessness and resentment at the limits that were perceived to be placed upon their bodies. Tones of 'othering' could be heard from participants who felt a disconnect with their body, which was letting them down.

> *"My brain is like quite active, quite alert, but my body is so tired I can't do anything. So it's almost like being trapped in a body that doesn't work"* (Jo).

> *"In some ways, it's a damaged body... [crying] it doesn't let me, doesn't let me be the person I was"* (Bianca).

> *"It is very scary, because it kind of felt like it was your own body working against you."* (James).

For some, this extended relationally, to believing they would let down other people, as well as themselves, which further impacted their feelings towards T1DM and their body.

> *"I do get frustrated you know, we were rowing the other week and we did a long row and I thought I'd taken enough carbs on board, but my blood sugar crashed so I let three other guys down in that boat, that sort of thing drives you to despair."* (Mark).

Most participants spoke of a physical impact of living with T1DM, ranging from day-to-day routine management, to experiencing or worrying about medical complications.

> *"I've already had one small bleed and background retinopathy so it's not just body image wise, but like functional, the functionality in my body, I suppose is a big worry and concern as well"* (Louise).
>
> *"You feel really vulnerable, and you feel like you're not, you're not in control of your life. And I think that's part and parcel with like, life expectancy, and what to expect with diabetic complications in the future… going blind and all of that" (Summer).*

These experiences were described as worrying and distressing by most participants, some made direct links between the distress of these internal physical experiences and T1DE behaviours.

> *"I don't think it was really about size or hating my appearance [the disordered eating], it was more about hating what was going on inside, I think rather than, you know, looking at my physical appearance"* (Bec).

Most participants expressed that the psychological effects of managing T1DM were more bothersome than the physical and this poor psychological management seemed to contribute to the diabetes mismanagement and disordered eating.

> *"...and the mental wear and tear that has on you over 10, 15, 20 odd years of being diabetic for so long…"* (Owen).

> *"Because I was just treated as somebody who was poorly, and not somebody who maybe had sort of something psychologically going on. I think that was the main reason really is that you know, a lot of things with diabetes is that you've got to have a good headspace to cope with diabetes. And I did not have that to the point where I actually caused myself quite a lot of harm"* (Bec).

2.3.1.2. Sub-category: Becoming your own clinician

Due to the need for T1DM to be self-managed, participants spoke of the difficulty coming to terms with the treatment regimes. It seemed participants had to take on a role of treating themselves, in a way more typically associated with doctors, nurses, or medical clinicians. Furthermore, fear or apprehension of engaging in these practices seemed to become tied to both distress, and disordered eating. I heard how participants felt a pressure and fear around needing to medically treat themselves. Self-management fears sometimes became so strong that participants responded with enforcement of strict rules around food.

> *"A nurse said, I'm really worried about you, you know, the next low you have, you could die. And literally after that happened, I came home and I kept my blood sugar at like 18. And I just couldn't, I was so frightened to bring it down. So what sort of happened after that comment and the fear is that I became, I was so scared of insulin, so it came easy for me just to have totally low carb diet and I did that for about a year. And I when I say low carb, like I would take one unit of insulin."* (Shauna, member-reflecting).

There was variation in how this was experienced by people, but many identified difficulties with processes such as injecting themselves or finger-pricking to test blood sugars.

> *"I got a fear of needles and so, taking injections got harder, and as the injections got harder to do, I started to do them less, hence lose weight. And then I just got a very strange relationship with food and pumping insulin into me"* (Jessica).

> *"I think pricking my fingers was worse than giving insulin" (Bianca).*

Others expressed no explicit fear of the regimes but that the treatment felt out of the ordinary, potentially positioning themselves within a medical or clinician role for their own body or acting in a way that is not typical. Again, this seemed somewhat more prominent in those diagnosed in adulthood rather than at a young age. Here, the 'othering' is apparent in not connecting to the self-managing role for their body.

> *"I've got literally no fear of needles at all, for anyone that did, I can only imagine it would be 10 times worse than that […] it's just the, the physicality of stabbing yourself with a needle"* (Louise).

For others, the task of injecting was not deemed distressing or problematic, but there were worries such as the effects of insulin, or the sensations associated with insulin treatment. For some, insulin quickly developed negative associations, most notably, around weight gain. Here, the use of an unwanted medication may push the 'othering' of the body.

> *"Insulin wasn't just a normal medication or anything, I just saw it as I was literally injecting the calories, I was literally injecting the fat sort of thing"* (Ava).

> *"And then when I start doing my doses again, and I take the insulin I should be taking, I can physically feel myself like plumping up into a sponge that's filled with water […] So yeah, shrivelled up sponge to a very swollen sponge is how it makes me feel when I take insulin"* (Jessica).

> *"I'd say because I've always been a sceptic about putting anything like foreign in my body, even paracetamol I'm a bit iffy... And now I had to put like this chemical inside of me that I didn't truly like or understand what it was made out of"* (Jada).

These challenges with treatment seemed to happen alongside the above experiences of being let down by the body, leaving participants at a discontent with their bodies. Some participants described a state of exhaustion and burn out with this self-management and told me about how they therefore stopped managing in the way they had been directed to. In this sense, T1DE appeared to be a form of regime non-adherence.

> *"And at the end of the day, whatever like illness, disease, anything that you have, you need your medication for it, but I was just refusing to take my medication, because I'd had enough"* (Ivy).

These types of experiences seemed most strongly reported in participants who had engaged in intentional insulin omission. It may be that this is therefore a particularly important category for this group.

4.3.2 Category: Falling short with diabetes

Stories and experiences of shame, guilt and failure were common amongst participant interviews. Participants told me about the standards they felt obliged to meet and reflected upon their experiences of *"never feeling good enough ...even when you're doing okay, you've got to do better"* (Ellie). Participants spoke of both internal pressures to be perfect, and external influences to meet an impossibly high standard.

This category was constructed by two interlinked sub-categories: ‘striving for an impossible perfection’, and ‘living in shame’. The category reflects the efforts of participants to continually strive to improve their self-management, whilst perceiving blame and holding embarrassment when this wasn’t met.

Alongside the experiences of living in a damaged body, this perception of falling short of a perfect ideal seemed to overlap in a way which pushed a distance between participants and their physical bodies; i.e. the process of othering the body. Here, othering seemed to happen because participants worked hard but did not see any tangible evidence of this.

4.3.2.1. Sub-category: Striving for an impossible perfection

Participants spoke about how they would strive for near-perfect outcomes despite intellectually recognising that some elements of blood glucose fluctuations may be out of their control. This aim for a perfect outcome seemed to be inevitably impossible, however, it seemed that the response to this was somewhat unbalanced, jumping to a sense of complete failure. Some participants spoke about this as an internal pressure, whilst others spoke of external influences from others which appeared to become internalised.

> *"The blame and shame that came with not managing, and not being able to be on top of it. Even though I was trying to manage it all by myself… as a child*" (Bec).
>
> *"You know, trying to remember that we are literally, essentially playing the role of an organ, which is completely impossible, I try to say that to myself".* (Alice, member reflecting).

Participants described desperate attempts to manage their diabetes well and this sometimes manifested as developing overly strict or rigid rules around food. In this sense, whilst participants were trying hard to keep themselves well, they inadvertently entered disordered and unhealthy management.

> *"I think it's imposing some kind of rules on what you can and can't eat, and reasons behind why you can or can't eat that thing, and creating like a narrative around food and kind of almost having… Erm, I think, ahh I don't want to use the word of obsession, but it can become an obsession with actively avoiding things."* (Charlotte).

> *"Because that amount of insulin and that amount of food was perfect for me to just stay like that [gestures drawing straight line]. I felt like if I adjusted it in any way, shape, or form, it was gonna go erratic and I just didn't want that. It was like a perfectionism thing to me. That was what diabulimia meant to me"* (Robyn).

4.3.2.2. Sub-category: Living in shame

Most participants described experiences of feeling shame, self-criticism, and blame, both in relation to T1DM and T1DE. Some reflected upon how blame could also be placed on specific foods or activities in addition to themselves.

> *"I never felt good enough, so I'd go to clinic and you know, my mum took me to clinic but I'd always come away from clinic feeling not good enough"* (Ellie).

> *"I would blame myself and say 'why did you eat that?' and then it casts that food then in a negative light"* (Charlotte).

Participants spoke of perceiving others to be judging or thinking negatively of them, particularly regarding consumption of food. This perceived judgement was described to be intertwined with stereotypes associated with diabetes.

> *"I always think that others are thinking bad about me and never focus what they say that I am doing well or that I was good at. So everything is about all the bad things the bad comments, or the things I think that they think... but no-one says"* (Bianca).

The overlap with the previous sub-categories was apparent in the way in which participants explained the shame and embarrassment linked to the self-management.

> *"To have to carry around, you know, like a big chunky testing kit and my insulin needles, and a fizzy drink and this that the other, was just, I just felt like… ashamed"* (Ivy).

Further to the fear of judgement, some participants recalled experiences of interactions which acted to confirm these fears.

> *"Because I would be actually told off, if I would eat something that was deemed not suitable for diabetes, you know. So there was lots of blame, there was lots of being told off about eating food"* (Bec).

> *"I even had, like, you know, family members where we go over for meal, and I'd just like inject myself really quickly and they'd be like, 'eww can you not, can you not do that here, can you like go to the bathroom', sort of thing"* (Ava).

4.4. Process: Being othered

This process was constructed from how participants described a feeling of being different to other people, and their bodies, and their need to navigate and understand their different body in the social world. In a similar way to how participants seemed to 'other' their own physical bodies in the process described above, here, participants were 'othered' within the world and in relation to their peers.

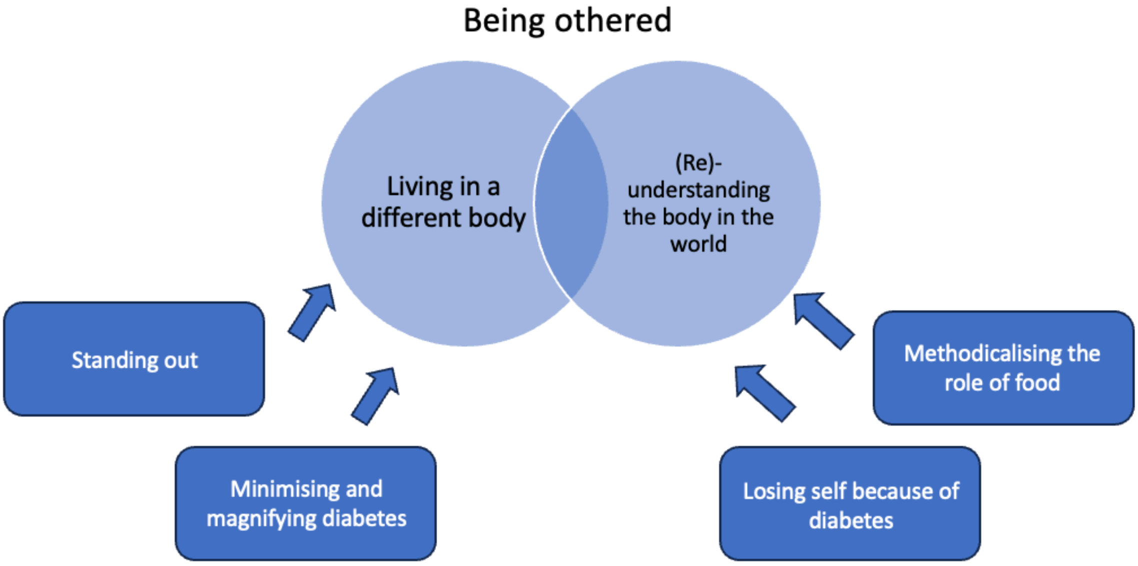
This formed from two interlinking categories; 'living in a different body' and '(re)understanding the body in the world" (each made up of two sub-categories shown in Figure 4). Whilst participants attempted to understand and navigate their own complicated experiences, they also talked about how others understood, or misunderstood, the role of diabetes in their lives. Ultimately, this created a sense of disconnect and a sense of the body being misunderstood and misaligned with their lived experiences and identity.

Alice, who shared their experiences whilst member-reflecting, spoke about how diabetes became all-consuming in her life, and became such a big part in how she felt she was perceived in the social world:

"Because I couldn't be [Alice], I was [Alice] with diabetes, or I was 'the diabetic" (Alice, member-reflecting).

Figure 4

Process: Being othered



4.4.1. Category: Living in a different body

Alongside the concept of the damaged or limiting body, participants spoke about feeling they were different to other bodies around them. For people diagnosed in adulthood, they reflected upon how they considered themselves to be different to who they used to be, or the body they used to have.

This category formed from two sub-categories, 'standing out' and 'minimising and magnifying diabetes', in which participants felt different to other people, and felt inundated by misconceptions held by others. These relational processes acted to impact how participants perceived themselves, or how they felt they were perceived by others. This seemed to go towards one polarity or another; being either over-identified as diabetic or lacking any validation of diabetic struggles. Being different and misunderstood in this way seemed to leave participants ‘othered’ relationally and by context.

4.4.1.1. Sub-category: Standing out

Participants described a perception of their bodies and body management as being different to that of other people. Whilst some participants described this a long-standing memory, others described a more gradual realisation of this difference over time.

> “*There were some boys in the year below me who used to kind of tease and laugh about the fact that I would have to inject insulin […] but it was kind of drilled into me that I was, at primary school, very different to everybody else”* (Ivy).
>
> *“It just didn't feel normal, I guess, initially, just, you know, having to sort of put a needle into yourself and doing that when you're out and about or at school sort of thing…”* (Ava).
>
> *“Primary I was no different to any of the kids […] it didn’t seem to be problematic in the way I viewed it until I was a teenager. And then all of a sudden, when you get a bit and more autonomy and you’re out more with your friends and different things, I started to realise actually, I was different” (Ellie).*

Some people reflected to the time of diagnosis, and how quickly and stark this experience of being different and standing out was for them.

> *“A teaching doctor came around with a group of student doctors and I must have been the only type one diabetic in the hospital at the time. And they kind of all just clustered around my hospital bed and were sort of taking notes, and he was talking and it felt very strange and alienating […] it felt almost like I was being put on exhibition as a… like a… when you go to the zoo and you look at animals and you think, oh that's interesting.”* (James).

Participants who were diagnosed in adulthood identified the change in the management of their own body, and this ‘different’ feeling also pertained to their own, pre-diabetic, body.

> *"The lady is telling me how to take the pins off and put them in the pen, and telling me, tonight you'll have to inject about five units. And it's funny, because it's, it seems like time went so fast, but so slow at the same time. And it's like, in that same day, my life just completely flipped and changed"* (Jada).

> *"Because he was an older person becoming diabetic after a lifetime of not being diabetic, it was much harder"* (Owen, talking about parent diagnosed with T1DM in later life).

> *"I was like grieving my past self, like I could do anything that I wanted without having to second guess and like, pre plan."* (Alice, member-reflecting).

Participants also described standing out due to visible indicators of difference, including direct effects such as injection sites, and indirect effects such as the consequences of consuming sugar. These physical differences seemed to interlink with the previously described sub-category of being in a body that is damaged.

> *"Physically to look at, you know, I'm scarred. There's a lot of scarring, and I've got a lot of scar tissue from injections and insulin pumps" (Jessica).*

> *"My skin was really quite bad last year […] and I think about like my teeth, and I'm like God my teeth are probably so much more like yellow than other people, because, like, the amount of sugar"* (Ivy).

> *"When I used to work in a bar, I got asked a lot about it [arm sensor] like, 'is that a nicotine patch?' or 'are you on tag?' someone said to me once, so I am conscious of it"* (Shauna, member-reflecting).

4.4.1.2. Sub-category: Minimising or magnifying diabetes

Participants discussed how other people understood, or misunderstood, the role that diabetes played in their life. Experiences were polarised, with some people feeling that diabetes was overemphasised by other people in the system (magnified), whilst others felt diabetes was underplayed (minimised). This misinformed view of the role of diabetes added confusion to the link between the body and the self and again led people to feel separate by physical body, in both polarities.

When participants spoke of others minimising diabetes, they spoke about a response of wanting acknowledgment or validation of the challenges of T1DM. For these people, this acknowledgement often only came when they were acutely unwell or having diabetes-related complications. In this way, T1DE sometimes offered access to the much-needed validation and support.

> *"I can remember planning stuff to make myself really ill …I don't really know what the outcome was, I guess I just needed somebody to notice"* (Bec).
>
> *"I was just so desperate to just get someone to care for me or to like feel loved, that in my head, I could try and like sort of provoke peoples maternal instincts by being small and by being vulnerable."* (Ava).
>
> *"I feel like there was a part of me, perhaps that loved being a victim in it"* (Robyn).

T1DE appeared to be one way in which participants were able to feel recognised or acknowledged in their T1DM struggle, even if this resulted in being very unwell.

> *"And I remember being there in A&E […] but at the same time I was having some attention, I was a bit of an attention seeker too then at that time"* (Bianca).
>
> *"So yeah, I always felt like I need to be an emergency for people to want to take care of me and to take me in and realise that things aren't going very well"* (Ava).

This experience extended to a down-playing of the challenges of managing diabetes by non-diabetics, leaving a mismatch between lived experience and perceptions by others. One participant described how this manifested at work when speaking to a senior colleague.

> *"And I said, 'in case I have a hypo so and so will take over, and I'll just treat it discreetly, or whatever'. And then like one of the like, the really senior people said to me, like, 'oh, can you not keep it under control?' as if it's like, as if it's that simple"* (Alice, member-reflecting).

Another participant reflected upon how this misunderstanding extends to doctors and medical professionals who are non-diabetes specialists. This presented a problem for participants, who may liaise with ED professionals in a hope of support but who might have limited understanding, making recovery more difficult.

> *"And then I think that's tricky, for not only just like general people, but doctors of EDs that aren't based around diabetes, because it is more focusing on like 'this is your plate' and 'have this much of this this type of food'..."* (Louise).

Conversely, participants who experienced others to magnify diabetes, reported feeling dismissed of all other parts of their identities. Many participants told me about a wish to be normal, and that magnification of diabetes prevented this. This seemed particularly apparent in participants diagnosed with diabetes from a young age and who had experiences of their diabetes being managed or supported by other people, such as their parents.

> *"I grew up hearing a lot of 'we've got to go because [Ellie]'s got to eat, we have to go because [name]'s got to eat, we can't do that because [Ellie]'s got to eat' and so I felt really restricted by food and I felt that, everybody's got to eat you know, but I felt it was so heavily pinpointed on the day and the structure would revolve around me"* (Ellie).

> *"And I remember I used to get really quite angry because my parents, really just being parents and being incredibly caring, but you know, it would get to half past nine, and I'd be*

> *still doing my homework, I'll be getting ready to go to bed or whatever and dad would call up to me and say, "have you done your nine o'clock?"* (Ivy).

T1DE appeared to offer some respite from this focus on diabetes and allowed people to detach from this identity somewhat or have reduced attention on diabetes.

> *"That was kind of the reason why I initially stopped doing it [injecting insulin], so it wasn't initially, it was never anything to do with my relationship with food or weight or anything like that, it was purely coming from a kind of place of just feeling a bit insecure and a bit just not wanting the attention on me, that sort of thing"* (Ivy).

4.4.2. Category: (Re)understanding the body in the world

Participants talked about how diabetes required them to consider their body more closely than others and that their bodies became a particular focus of their identity. For people diagnosed in childhood, they spoke of how they learnt to understand their body as they matured in the world whilst people diagnosed later in life spoke of how they needed to re-evaluate, change, or 're'-understand the role of their body in the world. This understanding seemed to be formed by both engaging in necessary elements of daily life, such as eating, and by the narratives and perceived role of diabetes by the wider system. Here, participants spoke about diabetes as being part of their identity, whether they liked this or not. Some spoke of how the diabetic identity was one part of the wider self, but that diabetes played a complicating role in understanding all the parts of themselves.

During member-reflecting interviews this category was elaborated to highlight the cultural and environmental factors at play. A participant described feeling that they struggled to fit into the British or Western dietary norms and drew attention to the fact that food selections that she made were often seen as 'restrictive' or 'disordered', when in fact, she felt she made healthy food choices which were simply not liked by cultural norms.

> *"I say it's the western world and the way they view food that's actually the problem. […] It's a struggle in the UK, where people are bringing in cakes to work. I work in a big company and I said, 'why are we having pizza lunches?' You bring in Domino's pizzas, I am diabetic, I know the impact that has on blood sugar. I know all these colleagues are going to be asleep at their desk after they've eaten that pizza, diabetic or non-diabetic. Why are we doing that? Why don't we have like, salad or like healthier options for this lunch situation?"* (Shauna, member-reflecting).

4.4.2.1. Sub-category: Methodicalising the role of food

Participants described that diabetes placed a complex focus on food and daily living. It seemed that food became objective, resulting in eating becoming a process or task, rather than something to be enjoyed. Some participants described the relationship as methodical and *"just mathematics"* (Owen), whilst others described being "*very emotionally invested in food and weight"* (Robyn). Either way, this seemed to contribute to the separation felt with the body, as participants relayed examples of needing to eat to treat hypoglycaemia, or not feeling able to eat certain foods to maintain stable blood sugars. In this sense, food could became rigid and limiting, losing its pleasurable features.

> *"You've got to calculate your fast acting insulin, you've got to work out what you're gonna do and if you're going to eat and those sorts of things can be mentally mentally very tiring"* (Mark).

> *"A bottle of milk, I don't look at this as a bottle of milk, I look at this as 15 grams of carbs, X amount of protein, X amount of fat, X amount of calories"* (Charlotte).

> *"But we can't release that control of carbs, no matter how healthy or unhealthy we are, we have to have a relationship with food that is different to normal"* (Louise).

> *"I hear my partner or my colleague say 'I've got a craving for pizza' ...Like I never crave really anything, like food for me is like, how many calories do you need to survive? It's not a, like, an indulgence. It's like just purely keep myself healthy and well, I don't see food as a treat or anything like that."* (Shauna, member-reflecting).

This unique, methodical relationship with food appeared to be important not only in the development of disordered eating, but in hampering recovery and progress.

> *"There was a constant, if my blood sugars went out of control, I would want to not eat, and you know the diabetic nurses tell you, if your bloods are high, don't eat, take insulin and that's our thing. It makes it very, very difficult for people with eating disorders to recover"* (Robyn).

Participants talked about how food, in particular sugar, was described as medicine which seemed to result in conflicting feelings. Whilst this still felt methodical for participants, there also seemed to be the opposite sensation of an emotive reaction to this, presenting a tension or struggle for participants.

> *"And I'd be there you know, sometimes, sometimes it just feels like I was like, gorging on sugar. And I hate that. And I still have days where my sugars might be low five times a day. And it's so infuriating, but you just you can't not have sugar, and you just have to have it"* (Ivy).

For some, disordered eating and hypoglycaemia treatment appeared to get entangled, maybe proposing a problem with this 'methodicalised' or objective view of food.

> *"I think when you have a hypo and you're kind of eating, binge eating to survive almost"* (Charlotte).

> *"I definitely feel like having a hypo can sometimes spur it on [binge eating], because it's that fear, firstly, of like, I've got to eat otherwise, my sugars are going to drop and it's going to end badly. But then I don't have that mechanism sometimes of stopping it"* (Summer).

Some participants spoke of the disordered eating as an escape from this methodical eating, allowing them to have a different experience with food and eating.

> *"I wanted to be the same as everyone else, I wanted to taste the same drinks and the flavours they were able to […]. So yeah, I started to drink that and I started to, instead of having lunch, I'd have the food I wasn't allowed to, you know, silly […] Then, fast-forwarding, I realised actually, if I gave myself too much insulin, I could eat more of the foods that I wasn't 'allowed' so I started to mismanage my insulin in that way first"* (Ellie).

One participant told me how re-establishing a relationship with food was an important part of T1DE recovery. It seemed that by connecting with food in a healthy way, she was able to align the body with her sense of self, starting to find enjoyment in food.

> *"But I found this love of cooking and foods, and I want to make all these amazing things and try these things that I've been prohibited myself from for so many years. And I just started making these things to eat them and I was loving it and I was, finding an enjoyment from doing that […] that's where most enjoyment was coming from at that time during my recovery, because I was like, finally I can eat food again"* (Robyn).

4.4.2.2. Sub-category: Losing self because of diabetes

Participants talked about how management of diabetes and eating often resulted in missing out. This appeared to impact how people understood themselves, by influencing the way they were able to engage with life and activities. There was often a social element to this losing out that participants experienced, again bringing a sense of social distinction for participants because of their bodies.

> *"I was a long distance runner, and I was thrown into this thing [diabetes] and I didn't understand how I was supposed to manage, and still keep my hobbies up and still keep my training up"* (Jada).

> *"Basically, it was all you know, things like not being taken on school trips"* (Bec).

> *"She was one of the people actually, who kind of took all of the foods that I used to enjoy away from me […] So I remember like watching every family member eat cake, while I didn't have any."* (Summer).

> *"I mean, today there's a load of cakes in the office because it's somebody's birthday. I didn't have one, which is you know, it would have been nice but no, I'm not going to have a cake."* (Mark).

Participants reflected upon an interplay between the diabetic identity and other parts of wider self-identity. This included an interplay with parts of the self, such as sexuality (Ellie), gender identity (Robyn), being an athlete (Jada, Mark), being good at their job (Ellie, Alice) and being a mum (Jessica, Bianca, Bec). For some people, diabetes brought about a threat to another part of their identity or self:

> *"Sometimes I feel like if I'm bigger, and I'm unfit, then to other people I look like I don't take care of myself, and that might reflect on other parts of my life, so, like as a mum"* (Jessica).

> *"And my mum was like, telling me it's getting kind of dangerous, you could pass out in the woods […] so she pulled me out of competing, and when you're so used to constantly training your body, it's, it's everything"* (Jada).

> "They [colleague] said along the lines of you know, 'you're really amazing at this, despite having to deal with your diabetes'. And it's like, in my own head, I've always had in my head

> that in my career I don't want to be good in spite of my condition. I'm good just because I'm good. I can do this because I can do this." (Alice, member-reflecting).

For others, there seemed to be a cumulative impact of the various identity interplays and how they came together to create a greater feeling of discontent.

> *"It was about that control, and I couldn't control it, couldn't control my diabetes, and I couldn't control my sexuality"* (Ellie).

Some participants talked about diabetes stigma as adding further emphasis on their body and a misaligned identity which didn't represent them. There was a grapple with recognising that stereotypes were inaccurate and misinformed, but still experiencing and living the impact of these system-held beliefs. For example, participants spoke about the way in which understandings of type 1 and type 2 diabetes are often blurred, or the view that T1DM results from being unhealthy.

> "*You know there's a lot of stigma around diabetes, there's a lot of stigma, a lot of jokes about it and I don't want to be put into a bucket you know of, fat and lazy"* (Summer).

Some participants even reflected upon how their own stereotypical understandings of diabetes were challenged upon diagnosis. For this participant, there seemed to be a challenge to her previously held belief of herself as an active and healthy person.

> *"But there was like, no sign of it. So it's like, I'm the first person ...why me, what did I do wrong? How, because you have that, type two, type two in your head, you're like, I am always active, I'm always doing this and that, and my mum didn't even allow us fizzy drinks up until we left the house she just didn't allow that in the house. So I was like, so set back"* (Jada).

4.5. Process: Taking control by being uncontrolled

A common thread across the above processes appears to be the importance of control, or lack of, in participants journeys with T1DE. Participants spoke of feeling out of control in various ways, such as lacking control of their bodies, their food choices, and of treating diabetes. Participants spoke about craving control, and that even when blood sugars or diabetes were well controlled there was always more work to be done, or anomalies out of their control. Many participants expressed how they found some power in engaging in behaviours or eating patterns which were (when viewed from outside) detrimental to their diabetes. In this sense, whilst others might observe the behaviours to have been uncontrolled, participants themselves described finding control in this experience.

This process was formed by the constructed understandings of two categories; ‘re-defining control’ and ‘urging to rebel’. This represents the discord experienced by participants in their search for control and how this was understood by others, and a strong urge to rebel against the pressures and rulings of diabetes. The combination of these experiences seemed to involve behaviours which, on the surface, seemed uncontrolled, but internally were offering power and ownership.

> *“I think that was also something to do with, well, if I can't be perfect, I can heavily mess it up”* (Ellie).

This participant spoke at length about the role of control and how mismanaging the diabetes allowed a feeling of some form of control. For this participant, changing their thinking and language from focussing on control, to instead thinking about management was important for recovery.

> *“That's why language matters, absolutely language matters, I am a big advocate I hate, I secretly judge people when they talk about diabetes control, because that tells me I'm always in control of it, and I'm not, so for me it's managing. What can I do on the 3 or 4 days to manage my health and not beat myself up because I haven't been able to control it?”* (Ellie).

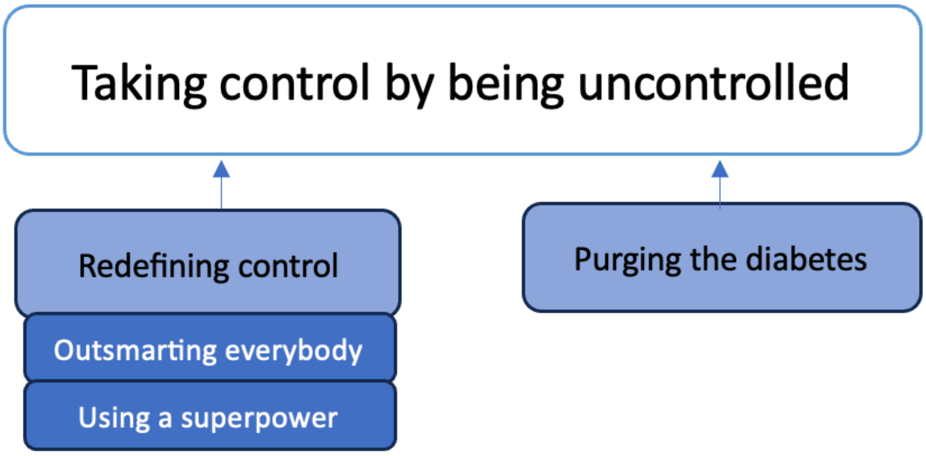
During a member reflecting interview, one participant spoke about how important they felt control was in the understanding of T1DE. They reflected that the search for control when feeling uncontrolled could manifest both in disordered eating, and in others ways.

> *"I think control and regime are like the two big words associated with diabetes and I think when you feel out of control with like your management, you can feel out of control for anything, finances you know I'd just go and spend all my money, I didn't care. […] And then sometimes I think well, I can't control that so I'm going to control the amount of food I eat, or the amount of times I exercise or I'll go control my emotions and put myself in a negative emotional space so I forget about the situation that I'm not controlling, if that if that makes any sense whatsoever."* (Alice, member-reflecting).

The process is visually represented in Figure 5 and shows the two sub-categories which form the 're-defining control' category.

Figure 5

Process: Taking control by being uncontrolled



4.5.1. Category: Redefining control

Participants described an apparent paradox in that by trying to find control, they engaging in behaviours which were considered to be uncontrolled in regard to their diabetes. This happened in varying ways for different people, for example some people engaged in excessive binge eating and others omitted insulin doses.

> *"I think it then evolved into, still fear, but needing a kind of obsession for control that was motivated by that fear. So needing to control my blood sugars and then developing kind of compulsive behaviours as a result of that. So either food restriction, or being sick, or doing a lot of exercise, doing a lot of cardio fitness. I think it became a way of exerting control over something that I felt I didn't have much control over, which was the disease and the diabetes."* (James).

Participants reflected upon how, in hindsight, these moments of compulsion and control were in fact uncontrolled, or at least appeared to be uncontrolled to other people. Participants seemed aware of the irony this presented to others.

> *"People always say like, well, wouldn't controlling your blood sugars make you feel like you're in control? And I was like, no, not controlling my blood sugars is what made me feel like I was in control"* (Jada).

> *"But control is a strength, you know, I maybe shouldn't view it as that, so that when you lose control it's a weakness and maybe that's where this comes from"* (Owen).

This category is constructed from two sub-categories; 'having a superpower' and 'outsmarting everybody'. By having a secret tool, in which participants felt they were able to outsmart people around them, including professionals, participants appeared to be redefining the idea of control. This allowed some influence and authority over their bodies, in which many had felt they were passively living in or being consumed by.

Some participants commented on the advancements in technology and how these had been helpful in alleviating some of the control-related distress detailed above, potentially positioning such technology as helpful in T1DE.

> *"I think, again, the pump and the Freestyle Libra absorb some of that control. Because the physical act of pricking your finger or doing injections is taken away. So your brain just changes its behaviour slightly and how it sees that condition."* (James).

4.5.1.1. Sub-category: Having a superpower

Disordered eating was spoken about as secret tool which participants became aware of whilst managing their diabetes. Participants would often describe this as being, to some extent, accidental or unintentional. Importantly, participants highlighted that these behaviours were often, at least to some extent, unknown or unapparent to other people due to being intrinsically liked to diabetes. Once discovered, people described that having a secret tool in which they were able to control fluctuations with their body became a powerful reinforcer. For many participants, weight loss or external bodily changes were not identified as the primary driver or goal of these behaviours, but rather, they gained a means of power over their bodies, the diabetes, and the wider system.

> *"I don't think it initially started as, oh let me do it to lose weight, but then when I started noticing that the weight was dropping, I was like, I have a level of control back, I feel good because I'm in control, I'm doing this and I'm the one in charge of whether my weight goes down or not"* (Jada).

> *"It was my thing. It was my secret, it was my yeah… I did feel in control of it."* (Bec).

> *"But, it was like the ultimate superpower, I can eat cakes and everything and not feel bad about it"* (Jada).

> *"And diabetes is all about control so, losing control for 10 minutes, or 20 minutes, or 30 minutes, there's a bit of escapism in that"* (Owen).

One participant also reflected upon the multifaceted role of diabetes in not only triggering and maintaining disordered eating, but also being able to hide or cover the disordered eating as weight loss was able to be explained by being unwell with diabetes.

> *"…because diabetes was the reason, but it was also the cover for me being able to constantly lose the weight that I was"* (Jada).

4.5.1.2. Sub-category: Outsmarting everybody

Alongside the newfound control in disordered eating and diabetes mismanagement, participants described how they were able to outsmart people around them, extending to professionals. This further redefined the control that participants had, reinforcing the impact.

> *"I thought I was you know, manipulating everyone, no one no one had any idea, you know, what I was doing and, you know, having no contact with anyone with type one diabetes sort of thing I just thought I was onto something, something that no one else was, a little secret sort of thing"* (Ava).

> *"You can have a very kind of secretive relationship with your diabetes, and a very secretive kind of dynamic with it, where it might not be apparent to everybody what you're doing, or how you're mishandling it, or how you're mismanaging it"* (Ivy).

All participants told me of their awareness of the risks attached to the disordered eating. They spoke about numerous diabetes-related risks including loss of vision, coma and limb amputation and they were aware that behaviours linked to poor management would increase risks. Overwhelmingly, participants told me that having the risks of mismanagement repeated and or simply being advised of how to manage diabetes by professionals was an unhelpful and unsuccessful approach. This could even have acted to further this sense of outsmarting everybody.

> *"So it's just like, there's nothing they can offer me if I go in, like, they're just gonna give me the same speech, I know what I should be doing, I know what the consequences are of what I'm currently doing."* (Ava).

> *"She would kind of give, you know, tips for how to control my diabetes, but she couldn't quite get the ED part of it as well. So like I was telling her I was like, look, I only feel like I can inject two units of insulin mentally, and she was just like, "yeah you have to inject more than that" and I was like "yeah I know" [laughs] […] So I felt like that was one of the most pointless appointments I ever had"* (Robyn).

4.5.2. Category: Purging the diabetes

As highlighted in previous processes and categories, participants described several struggles with their bodies and diabetes from which they sought escape. Participants told me about urges and drives to rebel against diabetes and its management as a form of control. I constructed this category from my understanding of participants journeys in which they wished to live a normal life, free of diabetes, this seemed to underpin these urges and rebellious drives. In one sense, participants seemed to be attempting to purge themselves of diabetes when engaging in T1DE behaviours, but this seemed to offer only a false sense of control to participants, which was temporary. For many, these experiences seemed to bring them back around to feeling out of control again, as they found themselves trapped by T1DE.

> *"And then I go back to just not using my insulin, eating what I want, and I'm pretending it [diabetes] doesn't exist"* (Jessica).

> *"So yeah I think that's, to me, that's what it means, it was just purging of a very heavy burden but still being able to live life... It's like pretending for me, pretending I'm normal, pretending like I'm everybody else or have the luxury of that like everybody else"* (Jada).

During member-reflecting, this idea was furthered by discussion that seeking escape would happen in relation to food and eating, but also in other areas of life. This seemed to be in a direct attempt to purge or escape this focus and feeling associated with diabetes.

> *"I remember just causing arguments with my partner, not having a problem, but just wanting to be upset about something else that wasn't about how bad my diabetes had been that day, so I'd purposely cause arguments just to try and escape the negative feelings I had towards my management that day"* (Alice, member-reflecting).

Some participants spoke of disordered eating as addictive behaviour, drawing parallels to drug use. Despite knowing the risks, participants were compelled to continue their engagement in these behaviours and described an escalating spiral of intensity. Whilst some participants did talk about insulin restriction and food restriction in this way, it seemed a particularly prominent experience for those with binge eating difficulties. This 'addictive' urge may represent the increasing attempts to purge in the face on an inability to truly escape diabetes.

> *"There's a bit of 'I don't care' ...like when you are fighting any addiction, which it is it becomes an addiction, you know, there's all sorts of self-loathing going on. But the bottom line is, you don't actually need any of what you are doing, you know, sitting downstairs at 4 in the morning stuffing my face, it's not a good scenario"* (Owen).

> *"…almost like an addiction, I've just got this need to eat, and there's almost no feeling with it. It's just I'm thinking about eating, and I've got to eat"* (Louise).

In some ways, it seemed that participants cycled back to feeling out of control, as they were unable to resist or stop these urges and drives associated with the ‘diabetes purging’. These participants spoke of how they ended up feeling that they were in an internal battle, or conflict with themselves to get themselves out of the cycle.

> *“And it became kind of like a war in my own head between the rational part of me really wanting control and not wanting to binge, but then the bingeing, just taking over completely, it's like a dark force that comes over your body”* (Summer).

> *A little bit of ‘I don't care about diabetes, I shouldn't be doing it but I am’, so it's a little bit of, I'm just gonna do what I want... even though I don't really want to do it [binge eating]”* (Owen).

4.6. Process: Finding validation in the body

This process was constructed by two categories in which participants seemed to describe finding value and validation in the form of their physical bodies, sometimes this was relating to body image and weight, whilst other times it related to blood sugar management. There was variation amongst participants around when this process happened and which of the above 3 processes it interacted most with. For some people, this validation in the body was found right from the start of their diabetes journey, whilst others described it as a secondary effect or something that developed over time.

> *“It was immediate, it was immediate. When I was in hospital and I had the feeding tubes taken out, you know I was given the menu, the hospital menu, and I was right, I can't eat any carbs, or you know I can only eat very limited carbs”* (Charlotte).

> *“It was just that whilst I was using it as a coping mechanism, that's when I realised like, oh, I'm losing a lot of weight. So initially when all of that started, you know, that wasn't my main*

> *goal. I wasn't specifically trying to lose weight, it was just sort of a consequence of, you know, just self-harming via, you know, insulin mismanagement"* (Ava).

Regardless of when this validation was found for participants, most described it as accidental, unforeseen, or surprising to them.

> *"So I wouldn't say that my eating disorder was like conscious. I think it happened because of something else."* (Jessica).

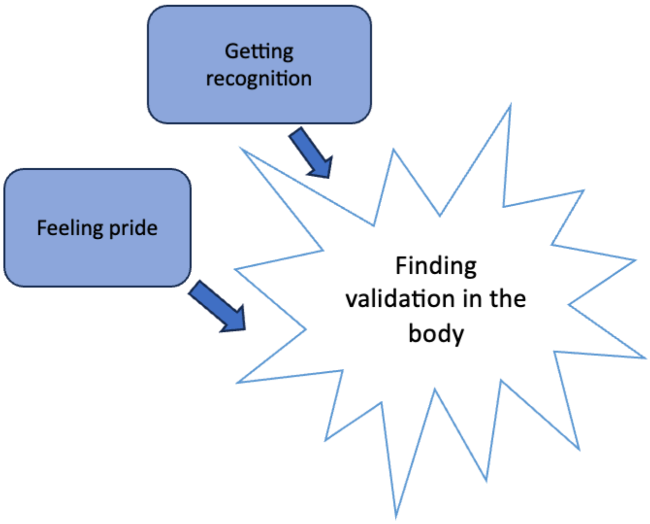
> *"A part me was kind of offended, I was hurt because I was like, 'Whoa, me? No no no, that's not me'."* (Jada, discussing when a therapist suggested she may have an ED).

> *"There was like a forum, like a support forum for people with diabetes and on there was something about diabulimia, and I clicked on it and there was like a list of behaviours and I literally ticked every box. And honestly, it's like as if someone had hit me across the face with an eating disorder"* (Ellie).

This process was made up of the categories 'feeling pride' and 'getting recognition' and displays the interplay between the internal experiences of being proud and the understanding of how others perceived them and found value in them (Figure 6). As shown by the spikey and unpredictable shape, this process interacted with other processes in varying and surprising ways.

Figure 6

Process: Finding validation in the body



4.6.1. Category: Feeling pride

Regardless of whether participants described weight loss as intentional or accidental, most reflected upon feelings of being proud of their bodies when losing weight. This seemed to be a powerful feeling in the context of shame, embarrassment, and guilt identified in concurrent processes; this pride may therefore have been a novel and pleasant experience.

> *"I had fooled myself into thinking I was this perfect human being and I had shaped myself, I'd perfectly chiselled my body into what it was, and I'd lost this weight that I'd had for so long"* (Robyn).

> *"And I started negating more and more and I was dropping weight, and I was like, I'm skinny! I love it!"* [...] *"So when I first like dropped the first, I think, two dress size in six months without lifting a finger, I was like I was, haha I win! So it was like, I felt like I'd achieved something with my body, and I felt so proud"* (Jada).

> *"And then becoming diabetic and realising the less insulin I took, my body started to lose, to attack other areas of my system, and then I would lose weight and I love the sensation of losing weight"* (Jessica).

For some participants, pride related more to keeping their blood sugar levels within specific ranges. It seemed that to feel this achievement in their bodies, they felt bound to meeting specific and rigid requirements, which came with pressure.

> *"Cholesterol, blood pressure, weight, all of that. I haven't got anything; all my markers are good and nothing outlying. So my diabetic body, I don't even acknowledge it to be honest. You know, all the stats and all of those things, I have always been top"* (Owen).

> *"Almost like in competition with myself […] and so I like seeing, you know, that I've achieved 82% in the green section today, and that I come away and I think at the end of the day, okay, this has been a really good day for me, I feel really good" (Ivy).*

> *"I don't know if you can see that [shows blood sugar reading], that's my readings for today. Right? 5.9 and it's been stable all throughout the day. Great, but the pressure that has put me under mentally..."* (Mark).

4.6.2. Category: Getting recognition

When discussing weight loss, participants told me stories or memories of how others had responded positively which acted as a reinforcer for losing weight. For participants who had described feeling that they were never good enough, or that they were bad diabetics, this recognition may be have provided a new and positive feeling of accomplishment.

> *"There's this picture on my Instagram and it was just after I got out the hospital, and I had lost loads of weight, and you know, I had people commenting and saying 'oh my God, you*

> *look so good! You look so well', and I always think back to that picture, because it's probably the sickest I've ever been in my life"* (Jessica).

> *"When I was at the point of having really high blood sugar I lost weight quite quickly and people would be saying 'you look so tiny, you look great, so skinny, what have you been doing?' and that kept me a little bit trapped at that time because I'd tried to lose weight before and now it felt like, this is so easy, people are complimenting me" (Shauna, member-reflecting).*

Participants also spoke of general societal messages that they were aware of relating to weight, which further drove a sense of validation in meeting these standards.

> *"But there was definitely that kind of, you know, pressure, like societal pressure and everything too. I remember at my school, it was like a big thing that everyone was like 'you have to have a thigh gap'"* (Ivy).

Some participants told me how they have found alternate ways to both take control and find validation in their bodies since their recoveries with T1DE.

> *"But I think I've learnt that there are other ways you can do that, like I have lots of tattoos, I like to cut and dye my own hair and things like that. So I think stuff like that can be important to identity"* (Jo).

> *"The gym for sure, having a set routine in that and being able to say, I came from this little innie minnie bag of bones to now having muscle and strength […] being able to flip the achievement from, oh look how much skin and bones I can see, to look how much strength I have, look how strong I am now, look what I can do with my power, I'm in charge of that"* (Jada).

4.7. Complexity of the interrelating processes - reflections

I noticed many overlaps between the processes, and this informed my decision not to number the processes and instead to attempt to pay credit to the circular experiences of T1DE in my representation. I noticed the interweaving nature of many of the categories, for example the category of ‘othering the body’ had overlaps with ‘being othered’. An example of this would be how participants spoke of learning to self-manage their condition within the constructed sub-category of ‘becoming your own clinician’ and how participants talked about the visible nature of self-management that is seen to other people within the sub-category of ‘standing out’. Whilst these touched on similar themes (engaging in self-management such as injecting insulin), they were constructed as distinct concepts as they were spoke about as having had significant and distinct meaning for participants (i.e. the pressure to manage this themselves verses feeling different to other people). The use of the overlapping circular visual aims to represent this, and to highlight that these distinct experiences acted to reinforce and strengthen each other.

The theoretical model aims to bring together in some form, the above categorised experiences, perceptions, and dynamics. Notably, participants appeared to reflect upon the relational role with their diabetes, they were able to explain and consider how this changes over time and context and how this interplayed with disordered eating and mismanagement. One participant nicely summarised this by reflecting upon the dynamic relationship she had with diabetes.

> *“You kind of have to just work out what your relationship with your diabetes is going to be like and what it's going to look like and how you're, gonna you know, get to a point where you're comfortable enough with it to want to look after it and want to like, not nurture it, but just like want to look after it and kind of have a stable relationship with it. Because I definitely see my diabetes as a relationship kind of thing that I have. I have a relationship*

> *with my diabetes, because, you know, I've gone through ups and downs with it, like I've neglected it, then I've not neglected it and I've looked after it, you know"* (Ivy).

This acknowledgement of considering T1DM as a relationship seemed somewhat different to the almost compelled responses of either hyper-focusing on or purging diabetes that were told about T1DE. With control and identity being key themes throughout participant interviews, it seemed an important step for participants was to work alongside diabetes consciously and mindfully in a way that allowed them to live their own life without consumption by diabetes, or use of disordered eating to cope. Of course, this will be a personal and individualised experience and therefore the proposed theoretical model aims to provide some form of template of understanding, with a recognition of varying experiences and forms of enacting such processes.

5.0 Discussion

5.1. Chapter overview

In this chapter I will discuss the above presented findings in relation to the research aims. I will consider the findings in the context of the existing literature, which will draw on literature relating to both T1DE, and existing understanding and theories about psychological adjustment to diabetes and relating to the physical body. I will then review and summarise the clinical implications of the findings with recommendations. Finally, I will consider the strengths and limitations of the research and pull together the core findings and reflections from this research.

5.2. Revisiting the research aims

I aimed to take an explorative approach to understanding the experiences of people with T1DE. I took a specific focus on the perceived role of the body and how people with T1DE experience their physical body as part of their whole selves and their social contexts. This was to build a theoretical understanding of T1DE, which can inform and support further research and clinical intervention in the area of growing clinical interest.

5.3. Summarising the findings

The research engaged with the experiences of people presenting with a broad range of disordered eating under the umbrella of T1DE. The findings suggest that there is a dynamic interplay of processes relating to the body and the self which underlie disordered eating in this population. The findings suggest that disordered eating is intrinsically linked to the experiences and understandings of diabetes and diabetes management.

Key processes included the separation or ‘othering’ of the physical body from the integrated self and the preferred identity, leaving people feeling disconnected and detached from their physical body. Further to this, the social and cultural context acted to reinforce the idea of the diabetic body as being fundamentally different and seemingly counteractive; Ellie highlighted the juxtaposition stating, ‘*it’s a lot to you know, bleed just to keep yourself alive*’, referring to the disconcerting nature of self-management. This seemed to present a friction for people as they lived with a lifelong condition which they felt separate and resentful towards but were required to constantly self-manage and monitor.

The findings highlight the important role of control within the experiences of T1DE, and disordered eating was suggested to offer a form of 'uncontrolled control', or a false sense of control, which allowed an escape from T1DM. As Jessica described this: '*I go back to just not using my insulin, eating what I want, and I'm pretending it doesn't exist*'. In this sense, T1DE can be considered as a medication or regime non-adherence, linked to emotional experiences relating to diabetes and diabetes acceptance. Validation of the body, both through internal pride and external recognition, appeared to act as a reinforcer for participants, resulting in this non-adherence manifesting as behaviours relating to bodily changes and fluctuations, such as weight loss. Disordered eating, as seen within the umbrella of T1DE, may therefore present one specific manifestation of distress or non-acceptance of diabetes.

The research points to an early suggestion that there may be varying profiles within the T1DE umbrella, in which parts of the presented theory may be more or less prominent, dependant upon the specific nature of how T1DE is experienced. For example, the processes underlying binge eating may present more heavily in one area (escaping control) and the processes underlying insulin and food restriction may present more heavily in a different area (being your own clinician).

5.4. Placing the research alongside existing T1DE literature

In this section I will look exclusively at the existing T1DE literature. Links to ED literature, health-related psychology, or general psychological theory will be considered under section 5.5. The existing T1DE literature had overwhelmingly highlighted the need for a truly collaborate approach between T1DM and ED services, which has been limited in implementation as presented in Chapter 2 (Hastings et al., 2021; Partridge et al., 2020; Zaremba et al., 2020). The current findings support this notion strongly, and potentially take a further step in positioning T1DM at the forefront of T1DE.

Across the processes, participants reflected upon diabetes burnout, non-acceptance of diabetes, and self-management struggles. Categories and concepts were heavily packed with these T1DM-specific struggles, while ED related concepts, for example as seen in the theme 'finding validation in the body' were described by participants as accidental, side-lines, unintentional, or secondary. This adds to the growing body of literature advocating for T1DM specific ED care and adds weighting to the call for specific and novel support rather than side-by-side treatment of 'co-morbid' T1DM and ED.

Each of the four processes from the findings will be considered in the context of the T1DE literature.

5.4.1. Othering the body

'Othering the body' pointed towards an anguish felt by participants in relation to their bodies, with a thread of failure running across the different categories. Some felt their body was failing and damaged, some felt they failed to meet perfect standards of blood sugar control; and some felt they failed in their self-management role. Undertones of shame, embarrassment, and criticism were woven amongst these stories. These findings are supportive of the growing research interest in self-compassion approaches for this population. Boggiss et al. (2020a) proposed that self-compassion may be a promising approach due to its focus on creating a more 'balanced' awareness of thoughts and emotions; establishing humanity; and practicing kindness to the self in the face of difficulties. The authors had suggested this approach due to the proposition of self-blame within T1DE which can be supported by the current findings. Even when participants in the study showed awareness of the unrealistic expectations that were being placed, they still reported internalised blame, suggesting the tools provided in self-compassion approaches may be of utility to support more adaptive and balanced self-talk, although it is important that these are T1DM-specific.

This process can be seen to compliment the CBT model theorised by Harrison et al. (2021) in which T1DM was distinctly named as impacting the development and maintenance of T1DE with diabetes-specific thoughts, emotional experiences, and behaviours identified. The current findings concur with many parts of the formulation, for example the proposal of T1DE patients feeling like 'bad diabetics' was apparent throughout the category of 'falling short with diabetes'. The current findings add an extra layer to Harrison and colleagues' work; suggesting the role, perception, and relationship to the body are vital parts of T1DE understandings too.

5.4.2. Being othered

Participants perceived themselves and their bodies to be different, visibly and invisibly, to those of other people. This supports the existing research in which T1DE has been noted as isolating and lonely (Hastings et al., 2016). The SLR in chapter 2 indicated early success with group interventions, highlighting shared humanity; genuine empathy; and shared experiences as useful elements of such groups (Boggiss et al., 2020a; Hage et al., 2023; Hastings et al., 2016). The current research heard that T1DM was constantly misunderstood, being either minimised or magnified, or fuelled by stigma and stereotypes. Connection with others who can understand, either via peer shared experience or increased training and support for professionals, could be vital to protecting people from this experience of being othered.

5.4.3. Taking control by being uncontrolled

This process adds a particularly unique yet complimentary finding to the field. Existing literature clearly documents the often troubled dynamic between T1DE patients and professionals in which patients report feeling misunderstood and professionals report feeling ill-equipped (Partridge et al., 2020; Zaremba et al., 2020). Of particular interest, were the findings from Zaremba et al, 2020 in which professionals reported feeling 'incompetent', 'demoralised' and 'emotive' regarding the challenges of understanding T1DE patients. Within the current findings, participants talked of T1DE as being a secret tool and likened by participant Jada to a *'superpower'*, in which participants were able to outsmart the people around them. It is perhaps therefore unsurprising that professionals are left feeling confused and incapable. The current findings suggest that the underpinning processes here are linked to a sense of control, but one in which T1DE patients create and re-define what is meant by control. This newly defined control appears to look quite the opposite to outsiders looking in, who may consider the behaviours 'uncontrolled'. This process therefore seems important in bridging the understandings between patients and professionals and proposes a flexible and individualist view of 'control'.

5.4.4. Finding validation in the body

This process seemed to be one which linked more closely to the ED-specific knowledges shared in the literature as being relevant in T1DE, for example the role of establishing pride and achievement in the body and the focus on body-image (Harrison et al., 2021; Treasure et al., 2015). The interesting addition proposed in this study, was the notion that this body-based recognition was often secondary and not only unintentional but sometimes unnoticed for some time by participants, with many reporting being surprised when their mismanagement was suggested to be an ED. Importantly, despite not being the initial or primary driver of the T1DE behaviours, once noticed and established, this became a powerful reinforcer, or as Jessica named it '*a rabbit hole'* which could quickly and dangerously escalate.

5.4.5. Experiences of male participants

Previous T1DE research has largely represented only females, sometimes due to recruitment samples targeting females only, and sometimes due to having no male uptake to recruitment attempts (Boggiss et al., 2020b; Dickens et al., 2015; Hage et al., 2023; Harrison et al., 2021; Hastings et al., 2016; Merwin et al., 2021; Takii et al., 2003). Whilst it was not within the remit of this study or methodological approach to conduct a comparative analysis based on gender, the study did recruit a mix of genders (13 females, 3 males, 1 non-binary), making 17.6% of participants male; whilst still being less represented than women, it was encouraging and insightful to have contribution from men. The experiences of all genders within the research appeared to fit within the developed model and there was no indication from my perception of any stark differences for male participants. However, it is notable that interpersonal, contextual, and societal factors were highlighted as playing an important role within T1DE. The role of gender as a cultural and contextual intersectionality is therefore implied to be one of many broader aspects of the social identity which are useful to consider when understanding individual experiences and identities.

5.5. Theoretical implications

5.5.1. Situating and understanding control

In theorising the development and maintenance of the ED Anorexia Nervosa (AN), Fairburn et al. (1999) suggest that eating becomes a focus for gaining a sense of self-control which is powerfully reinforcing and linked to feelings of self-worth. This idea has become prominent in ED literature and has been used to understand the processes behind several forms of ED, for example, Schlegl et al. (2020), suggested that disordered eating within people with EDs increased during the COVID-19 pandemic, in which external context limited the control people had over their own lives. The current research has also highlighted an important role of control within the T1DE population, although this might present in a way unique to how this is understood within the non-diabetic ED population. Firstly, the process identified in this research of 'finding validation in the body', seems to some extend to align with the above theoretical understanding of ED, suggesting that people with T1DE may, in a similar way to AN, find a sense of control and accomplishment relating to food intake and compensatory behaviours. However, the current findings suggest a specific and complex layer of control within T1DE, which may not be apparent, and may even be present as contrary to the ideas of control held by others, including health professionals.

Froreich et al. (2016) summarise that whilst control has been linked to EDs in the literature for some time, problems arise with the construct of control, and how this is consistently understood and defined. They aimed to present an operationalisation to the idea of control and to explore which were most relevant in the context of EDs. They found that feelings of ineffectiveness (being inadequate and lacking control over one's life) and fear of losing self-control were two variants which were predictors of disordered eating. The current research can be seen to support the first variant of control (ineffectiveness), as the findings highlight the role of shame and self-blame in striving to meet the impossibly perfect standards of replicating the bodily function of producing insulin. However, relating to the second variant (fear of losing self-control), the research suggests a differing experience for people with T1DE. Many of the participants spoke not of a fear of losing self-control, but of a state of feeling already under the control of diabetes and the diabetic body, with significant limits to their own control. In this context, people spoke of a sense of apathy or diabetes burnout in which they sought an escape of their constant attempts to fight for control. Rather than fearing a loss of control, participants were seeming to *succumb* to a feeling of being unable to control the diabetes and so *redefining* control to take back some autonomy. In this re-definition of control, participants spoke of control in the form of 'messing up' or 'being uncontrolled', which may to observers seem contrary to the idea of 'control'.

Budd (2017) theorised that women who engaged in disordered eating (non-diabetic) did so as a method of, or pursuit of, control. She reported that for some, control was a reaction to when things had gone wrong in peoples' lives. The current research supports, to some extent, this idea adding a diabetes specific lens that a pursuit of 'control' may happen when diabetes feels poorly managed or is 'going wrong'. Budd also found that disordered eating in non-diabetics was driven by the mirroring of the behaviours of others, and women reported feeling spurred on by believing or knowing that others were engaging in similar behaviours. The current research suggests an interesting contrast to this idea in the diabetic population, in which participants talked of their disordered eating as being a secret that was unknown to others. Some participants even commented how they believed they were the only person that knew about specific mechanisms such as insulin omission. Given the presented theory also positions emphasis on 'being othered', it may be that participants were more likely to find a comfort in a behaviour which felt unique to them, than one that felt aligned with that of others who were perceived separate to them.

5.5.2. Theorising in clinical health psychology

Cornish & Clark (1987) propose that people typically employ the Rational Choice Theory in which behavioural decisions are assumed to be underpinned by fundamentally rational logic as per a weighing up of the costs and benefits relating to the decision. This theory is used to consider how people make healthcare-related decisions and informs how professionals assume patients will make decisions, i.e. medical teams may assume patients will make the choice that seems to be the most rational from their professional perspectives (i.e. to follow diabetes dietary and insulin regimes). Morris (2020) proposed in her research of the lived experience of diabulimia that this rational choice position may neglect the emotional and contextual complexities of patients engaging in insulin restriction and highlights that the individual factors behind their choices are therefore left unexplored. The current research builds upon this suggestion, by indicating that the T1DE participants often felt misunderstood by their care teams, families, and broader systems. They acknowledged that others seemed not to understand their perspective, and many reflected upon how professionals would repeat the same health advice over and over, despite participants being well aware of the information and risks. Here, it could be considered that professionals may feel the need to inform of health advice in a way which might promote what they *believe* to be the rational choice. Instead, patients may have a multitude of hidden or personal factors informing this seemingly straight-forward choice.

Psychological reactance theory (PRT) suggests that when a person has a perceived threat to their freedom, they experience a motivation to restore this freedom and sense of autonomy in direct response to the supposed or real threat (Brehm, 1966; Brehm & Brehm, 1981). This drive is thought not to specifically relate to seeking a true freedom, but rather, the perceived loss of freedom is the significant factor which triggers a reaction. PRT is used to understand responses to health advice communication in several physical health conditions (Crano et al., 2017; Rosenberg & Siegel, 2018). Research into this has expanded since its introduction, for example Han & Kim (2019) have added the important role of value-orientation in psychological reactance and behaviour intention relating to diabetes healthcare messages. The current research further contributes to these ideas, providing first-account experiences of how diabetes related advice, and even diabetes itself, can pose a threat to the self-control and identity of a person. Furthermore, it even pushes the person to be othered from their environment and their own physiology.

The findings draw attention to the blurry lines between professional and patient which may present in the self-managed condition of diabetes. In the sub-category ‘becoming your own clinician’, I heard how participants felt pressure to take on the role of a medical professional for themselves, monitoring and treating the body daily to remain well. Cole (2013) describes how patients and professionals typically ascribe to an implicit understanding of the medical professional as being the ‘expert’ within physical health contexts. It is suggested that this is typically comfortable and accepted for both parties, in which the doctor or nurse acts in a clinically paternalist way. The idea of patients ‘becoming their own clinician’ as proposed could unsettle this unspoken arrangement for both patients and clinicians. I believe an acknowledgement of this unique co-relation between professionals and patients is significant when understanding T1DE, as patients may be grappling with coming to terms with the remit of this new and pressured identity and role. Alongside this, the professionals, who are accustomed to being in the expert and medicalised authority position, may also be new to this dynamic.

Bringing together the ideas of PRT and the new professional-patient dynamic created by self-management, these findings suggest that professionals and diabetes services may benefit from avoiding the urge to persuade patients towards certain behaviours. Instead, aiming for a collaborative, aligned, and empowering approach may be useful in supporting people with their health management, and therefore disordered eating.

5.5.4. Embodiment in theorising T1DE

The findings support the ideas relating to how the human body interacts with the social world and society, being intrinsically interlinked with culture and context (Shilling, 2012; Dixon, 2015). The research has highlighted the interpersonal nature of T1DE and how experiences of T1DE, diabetes, and disordered eating all have grounding within relations towards other people, the social environment, and societal expectations. Whilst participants spoke of the physical experiences of T1DE (such as the need to inject insulin into the body), their narratives were entangled with social interpretations of these (such as being different in school, being looked at on the train, being asked to inject in private). It seems impossible to isolate the physical body in a raw or uncontaminated way from their social contexts and journeys within the relational world. The research therefore supports the theorisation of T1DE as a complex construct which is impacted by not only individual experiences, thoughts, emotions, and behaviours, but also by the interplay of human and environmental factors. This positions the role of embodiment and an understanding of the role of the body within the world as a potentially central part of supporting people with T1DE.

Notably, many participants identified a misalignment between their perceptions of a 'damaged' diabetic body, and their sense of self and identity, drawing attention back to the mind-body link discussed in the introductory chapter, see section 1.3.2. This misalignment seemed perpetuated by the processes of 'othering' of their bodies, from both the bodies of other people, and for some, their own pre-diabetic body. This idea of misalignment was often described to be related to distress and discontent for participants. This idea is supported by recent findings from Embaye et al (2023), who found an association between diabetes distress and disordered eating behaviours. Therefore, T1DE could be seen as emerging from distressing embodied experiences, in which participants were 'finding control by being uncontrolled', these ideas and processes are shown in the variations of the GT model creation in Appendix L.

This theorisation complements the ideas of philosopher Merleau-Ponty (as cited in Iacovou & Weixel-Dixon, 2015) in which humans can be thought of as both *having* a body, and *being* a body. Participants did not describe passively existing within a body, but instead, their bodies and the diabetes were entangled with their experiences within the world and alongside other people. Shilling

(2012) proposes that the body can be seen as a biological and social entity that is unfinished as it enters the world and is altered and transformed by social participation. Here, T1DE seems to transform and evolve from complex progresses in varying domains including physical, psychological, social, and environmental, supporting the need for holistic and multifaceted understandings and support.

The prospect of ‘body projects’ discussed by Balfe (2009) and Shilling (2012) can also offer a framework to understanding the dynamic structuring and restructuring of the body and the self that was proposed within the findings. Participants spoke of yearning for a ‘normal body’ which was heavily influenced by their social context, and T1DM appeared to act as a limit, placing constraints on how fully participants were able to align with preferred identifies (e.g. possible ideals of ‘the mother body’, ‘the athletic body’ or ‘corporate body’).

Laing (1960) discussed the idea of the ‘unembodied self’; which he suggests is ‘divorced and detached from his body’ when understanding psychosis (p69). He describes a radical split in which the body is felt as false and detached; these ideas have parallels with the way participants seemed to ‘other’ their bodies or felt their physical bodies misaligned with their true identities, and in people diagnosed in later life, their previous self.

5.6. Clinical implications

The findings support the existing calls for T1DE to be considered in a multidisciplinary and collaborative way, forming support by merging expertise and experiences, rather than viewing T1DE as two distinct conditions which are treated separately or side-by-side. This is supportive of recent NHS-funded pilot-services which have embraced a truly integrated approach (Alicia et al., 2021; Partridge et al., 2020).

As described in section 5.5.2., healthcare professionals may have a rudimentary view of how patients may utilise healthcare advice in the broader scope of their context and may assume patients will make, what they consider to be, ‘the rational choice’ about their care and self-management. It is therefore possible that healthcare professionals may assume that when patients display behaviours inconsistent with the advice that it is due to a lack of understanding and may respond with repetition of advice or instruction. This research suggested that participants were in fact aware of the diabetes related advice and participants explicitly discussed the unhelpful nature of the reiteration of this. It is therefore recommended that health professionals instead seek to enact curiosity with patients about their perspectives and experiences, opening up the conversation to hear how the patient views the management of their diabetes. It is recognised that this may be uncomfortable for professionals, who are trained to provide patients with healthcare advice, and therefore it is recommended that supportive supervisory spaces should be available for medical professionals working directly with patients experiencing this complex interplay of physical and psychological health decisions.

As outlined in section 4.5.2., this research suggests that PRT may inform the responses of people with T1DM and T1DE when faced with diabetes and diabetes related health advice. It is therefore recommended that when working with T1DE, professionals should avoid the use of instructive language which can present as controlling or present a threat to freedom. Instead, Rosenberg & Siegel (2018) propose that use of autonomy-supportive language and conversation offers an alternative to an instructive or controlling directive which can trigger the reaction posited in PRT. Miller et al. (2007) provide examples of how this may be achieved, for example replacing instructive terms such as ‘should’ and ‘must’ with more suggestive terms such as ‘maybe’ and ‘perhaps’. As above, this could be difficult and novel for medical professionals and supervisory and reflective spaces are advised to support with this.

Diabetes professionals and patients may benefit from jointly considering the role and dynamic of their relationship and recognising how this may be unique to other experiences of physical health care. Due to the need for life long self-management, patients may sit much closer to the ‘expert role’ than is typically considered within physical health appointments. It is recommended that patients are supported in this highly pressured role and reminded of outlets for support and further advice or peer sharing where appropriate. Professionals and patients may benefit from discussing the pressured role that the patient is required to take in their indefinite management of the condition. Indeed, throughout several interviews, participants talked about a wish to have had more pre-emption about the struggles of managing diabetes; *“I don't know if it's something that can be introduced on the visits[…] getting ready for what might come, or when it comes” (Owen, talking about psychological impact of T1DM).*

The findings suggest several therapy-specific recommendations for psychological therapy in the context of T1DE. Examples include:

- Using the physical body as part of therapy, this may include both establishing educational links between the physical and psychological sensations, and utilising the physical body and movement within therapy. Bell et al. (2019), summarise the ways in which ‘chair work’ (externalising the ‘problem’ and liaising with it on an empty chair) within Compassion Focussed Therapy (CFT) was effective for patients with depression. They used strategies such as enacting, physically responding, and physically situating different parts of the self on physical chairs. Not only did these strategies support people to observe more rationally the differing parts of their selves, but it also supported people to use and observe their bodies and bodily responses to understand their experiences. As the experiences of T1DE are so interwoven with the physical body, such approaches may be beneficial.
- Supporting patients with the identification of a psychological ‘middle ground’ in the management of both their diabetes and the idea of control. The results highlighted the tendency for gravitation towards extremes, for example having perfect management, or having completely failed. Therapeutic approaches may take a position of supporting patients to challenge this. This would build upon the existing evidence base for supporting the

challenging of perfectionism in both the diabetes population (e.g. Powers et al., 2017) and the eating disorders population (e.g. Bardone-Cone et al., 2007). This corroborates the use of compassionate approaches and the focus on learning to show gentleness towards oneself, as found within the literature review in section 2.4.5.

- Supporting the establishment of pride, accomplishment, and self-validation outside of either diabetic control or body weight. Therapeutic approaches which highlight strengths and support the setting of value-based goals in order to reach meaningful achievement may also be useful in support of this. This could include CFT or ACT approaches.
- Taking a person-centred and individually-led approach to therapy. This may be particularly important given the findings relating to a lost sense of self and identity within T1DE. The role of therapy could act to support people in finding their multi-faceted selves, building an identity alongside, but not led by, diabetes and the diabetic body.

The findings promote the use of a multidisciplinary and holistic approach to treatment and intervention with T1DE. The proposed theory displays the ‘othering’ that is deeply embedded within T1DE, and so distinctions and separations between services and physical and psychological provision are likely to only further this sense of difference and isolation. Indeed, many participants did discuss within their interviews how they felt different to their peers who they were grouped with as being supposedly similar (e.g. when attending binge eating support groups, but being the only person with diabetes). Instead, this research urges distinct professions to align and use their knowledges concurrently to support people with T1DE and confront their experiences of being othered via validation and understanding.

Diabetes related technology was discussed by most patients in some capacity. Most notably, participants spoke of the use of technology such as the FreeStyle Libre and insulin pumps as reducing the burden of diabetes management or pressure upon the self to manage and medicate the body. This study did not specifically aim to explore the role of such technological developments, but as many participants brought this to their interviews it seems an important part of their journeys, particularly in the indication that the technology alleviated the pressure and distress associated with diabetes management. Means of blood glucose monitoring and insulin administration may therefore be significant in T1DE and it may be beneficial for options to be robustly discussed and weighed up with patients.

5.7. Evaluating the research

A full quality appraisal has been presented in the methodology chapter, section 3.7, which evaluated the research against qualitative and GT specific criteria. From this, I am confident that the study meets the criteria laid out in guidance for conducting rigorous qualitative GT research. Below I will reflect on the broad strengths and limitations of the research, in particular thinking about its generalisability.

5.7.1. Strengths

The research has a strength in filling a research and literature gap in relation to disordered eating and EDs in the T1DM population. Whilst previous research has highlighted the prevalence rates and increased risk of disordered eating within the population, research into the experiences of people living with this has been limited. This is important given that there are several recent and newly developing pilot trials and services emerging in consideration of treating and supporting this group. By providing preliminary theoretical concepts of T1DE, support and direction can be offered to this growing field of research.

Another strength is that whilst the study specifically looked at the T1DM population, it took a wide umbrella approach to recruitment, meaning that a range of people with varying disordered eating presentations were interviewed. This was a useful approach for early research into the field as it helped to draw some overarching concepts and conclusions and captured a wide range of experiences. The GT model encouraged me to utilise theoretical sampling in order to expand the model and seek out specific participants, this was something I employed in order to better capture the experiences of men, and the experiences of those with binge eating behaviours. Furthermore, the research is grounded in the experiences and journeys of people who have direct lived experience of T1DE. This is important given the aforementioned lack of understanding within the professional and clinical field. With the option of online interviews, the research was able to reach participants from varied localities across the UK, meaning that participants did not come from one specific service and came with differing experiences of support from their local health services.

The research situates itself within the sphere of Clinical Psychology, whilst recognising the role of the body, physiology, and medical care. This is an important strength as it supports the aim for holistic care, honouring the connection of the body and the mind. Indeed, supporting this, participants in this study talked about the need for collaborative understanding and care and many named that the psychological support relating to their diabetes had been starkly lacking. By positioning health related research within the Clinical Psychology sphere, a unique insight can be gained into the multifaceted human experience.

5.7.2. Limitations

A limitation of the study is the use of a volunteer sample who opted in to the research from seeing recruitment posters and adverts, either in clinics, online forums, or social media accounts. This is likely to have been limiting. People motivated to contact the researcher and take active steps towards participating in this research may be more likely to have had specific experiences motivating them towards involvement, for example, they may have felt excluded from service support. It is also likely to have captured people at a specific place in their recovery journeys; several participants spoke retrospectively about their experiences with T1DE, as some considered themselves to be distanced from T1DE at the time of the interview. This may have impacted what was shared, and relied upon historic memories rather than current experience. This form of recruitment relied on people either actively being within NHS services, or using online platforms in the context of following or engaging with diabetes and/or disordered eating content. It is possible that this form of recruitment may yield participants with similar experiences and who have accessed similar content (e.g. on specific social media accounts).

Whilst I was able to recruit people from varying contexts, there was still a lot of homogenies within the demographics. For example, 15 of the 17 were White, with 14 being White British, and 13 of the 17 identified as female. It is possible that a more equal demographic mix of participants may have yielded different results and consequently a different theoretical construction. The generalisation of these findings is therefore limited and should be taken with caution. In line with the epistemological stance of the research, it is recognised that the knowledges that I have constructed are based on how I interpreted the data. I therefore sought to broaden my knowledges through my participant pool but did not seek a definitive truth from them.

5.8. Further research

This study has looked at the experiences of T1DE under a broad umbrella, encapsulating several forms and presentations of disordered eating. From the concepts and categories that make up the theory, it appeared that there may be some distinct or nuanced profiles of T1DE in which there might be varying underlying processes. Further research may therefore look more specifically at the experiences of these distinct profiles, for example, further exploring the role of ‘uncontrolled control’ in T1DE binge eating, or further exploring the role of the pressures of self-management or ‘being your own clinician’ in insulin or food restriction.

Most participants for this research were recruited via T1DM community outlets. It is possible that people presenting in ED communities may offer differing perspectives or experiences. This is particularly important to consider given that one of the major conclusions from the findings has been of the emphasis of the diabetes-specific experiences, over a typical ED understanding. Research may therefore look to explore experiences of people with formal ED diagnoses, people accessing ED services, or via ED specific charities.

5.9. Final reflections

The relationships and dynamics between the processes and categories I constructed within the research is to some extent a messy and convoluted picture. This may somewhat mirror the messy presentation of T1DE within the current clinical and theoretical landscape in which neither diabetes services or ED services in isolation have a strong evidence base for supporting people with T1DE. I have noticed how, at times, I strove to form neat and clean categories as I developed my theory, and I wondered whether this may mirror the endeavours of patients, researchers and professionals to categories and fit experiences of T1DE into clear boxes. I have acknowledged the overlapping and interrelating nature of the categories in the model and the potential of some areas holding greater weighting for different presentations or profiles of T1DE. Upon reflection, whilst this feels intricate and blurry, it reflects the human experience and the individualised processes that participants experienced. Indeed, in her guidance for quality appraisal of qualitative research, Tracey (2010) advises that postmodernist research can often be presented in a way which shows the inconsistent and fragmented nature of a phenomenon or landscape. I am also reminded of a comment made by the participant Bec, who repeatedly told me that she was baffled about why she had previously engaged in T1DE behaviours; she felt the only way to conclude the experience was *"just bizarre… bizarre and strange behaviour".* This reminds me that T1DE was likely messy and confusing for participants too.

5.10. Conclusion

This contribution to the growing research pool in the field of T1DE highlights the role of the physical body and perception of the body within the social world. The findings propose that T1DE can be understood by an interplay of processes including the self-led othering of the physical body; being othered by relational dynamics and the social world; and ultimately a grapple for control which can present in surprising and seemingly uncontrolled ways. Many of these processes were underpinned heavily by experiences related to T1DM, with many experiencing distress, non-acceptance, or frustration with their diagnosis. Participants found a validation in the body which reinforced disordered eating or diabetes mismanagement and suggests that T1DE may be one specific manifestation or form in which diabetes distress can present. Varying specificities within the T1DE umbrella were hinted to be experienced, which could be an avenue for future research.

By positioning this research within the remit of Clinical Psychology this research has drawn focus to the psychological, social, and contextual factors which are integral to the understanding of the experiences of people living with T1DM. This moves away from viewing the body solely as an objective entity in which health and illness simply exist or are passively observed.

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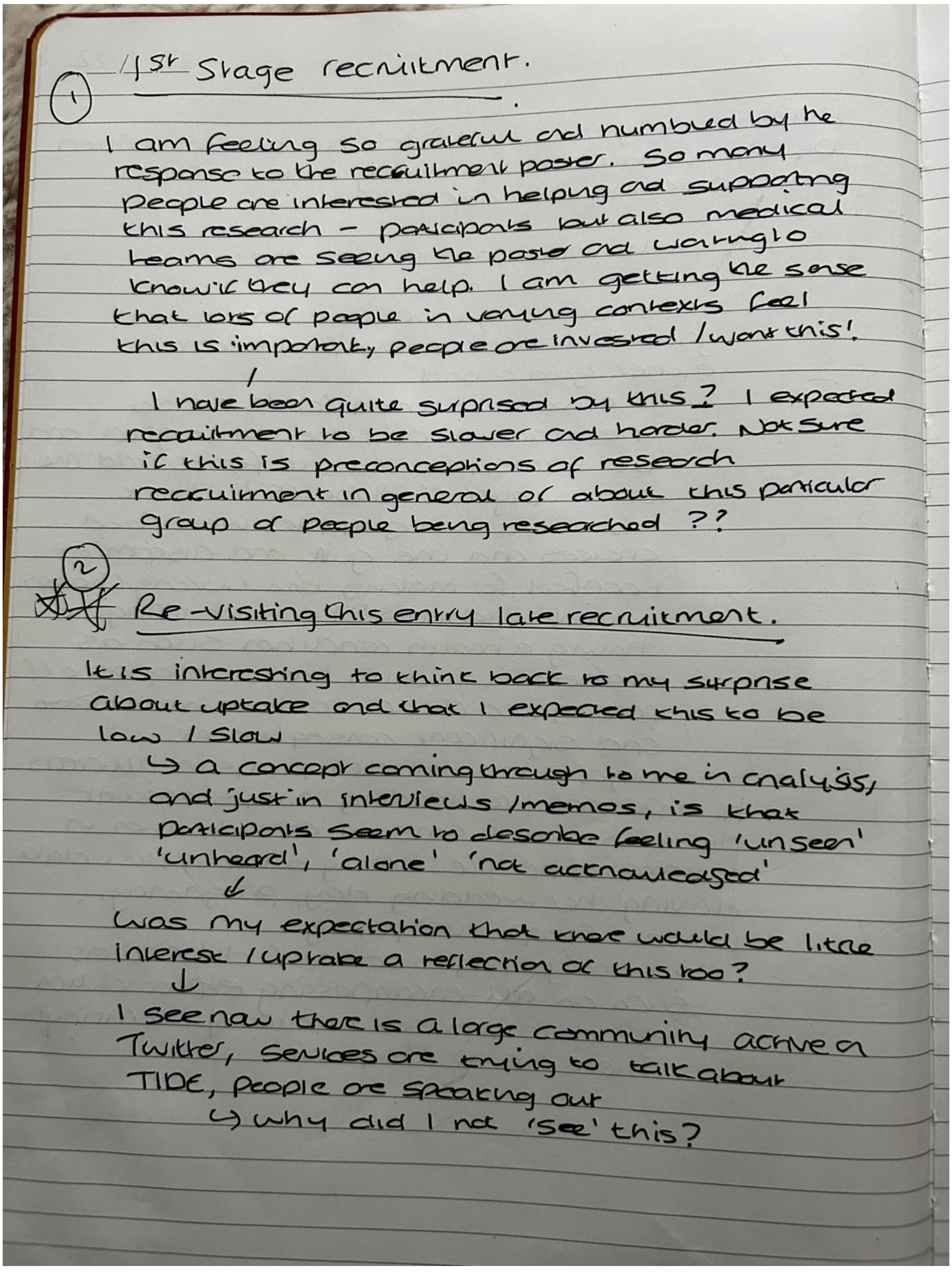
Appendices

Appendix A: Extracts from reflective journal



① 1st Stage recruitment.

I am feeling so grateful and humbled by the response to the recruitment poster. So many people are interested in helping and supporting this research – participants but also medical teams are seeing the poster and wanting to know if they can help. I am getting the sense that lots of people in varying contexts feel this is important, people are invested / want this!

I have been quite surprised by this? I expected recruitment to be slower and harder. Not sure if this is preconceptions of research recruitment in general or about this particular group of people being researched ??

② Re-visiting this entry late recruitment.

It is interesting to think back to my surprise about uptake and that I expected this to be low / slow

↳ a concept coming through to me in analysis, and just in interviews / memos, is that participants seem to describe feeling 'unseen' 'unheard', 'alone' 'not acknowledged'

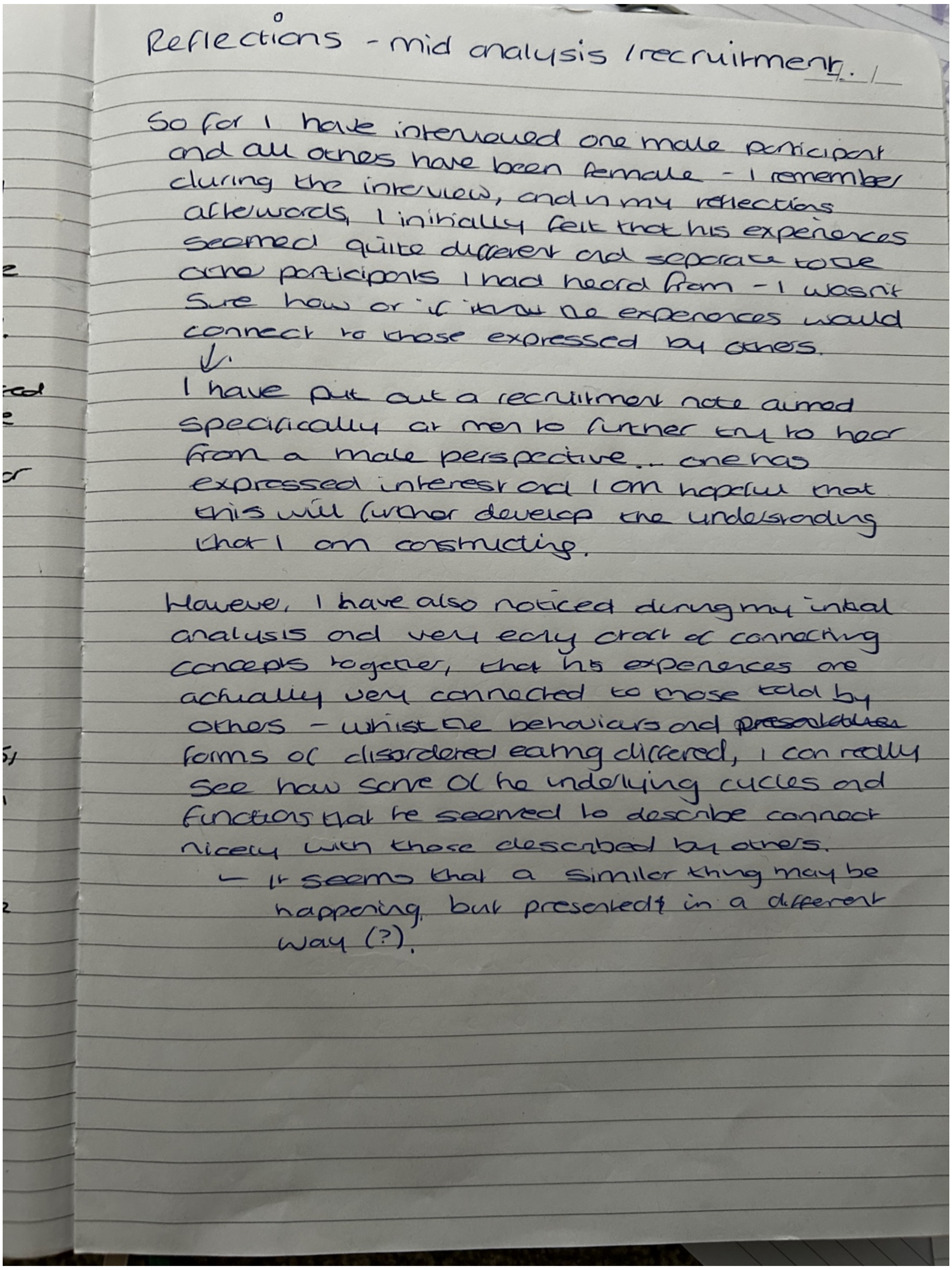
↓

Was my expectation that there would be little interest / uptake a reflection of this too?

↓

I see now there is a large community active on Twitter, services are trying to talk about T1DE, people are speaking out

↳ why did I not 'see' this?



Reflections - mid analysis /recruitment 4. /

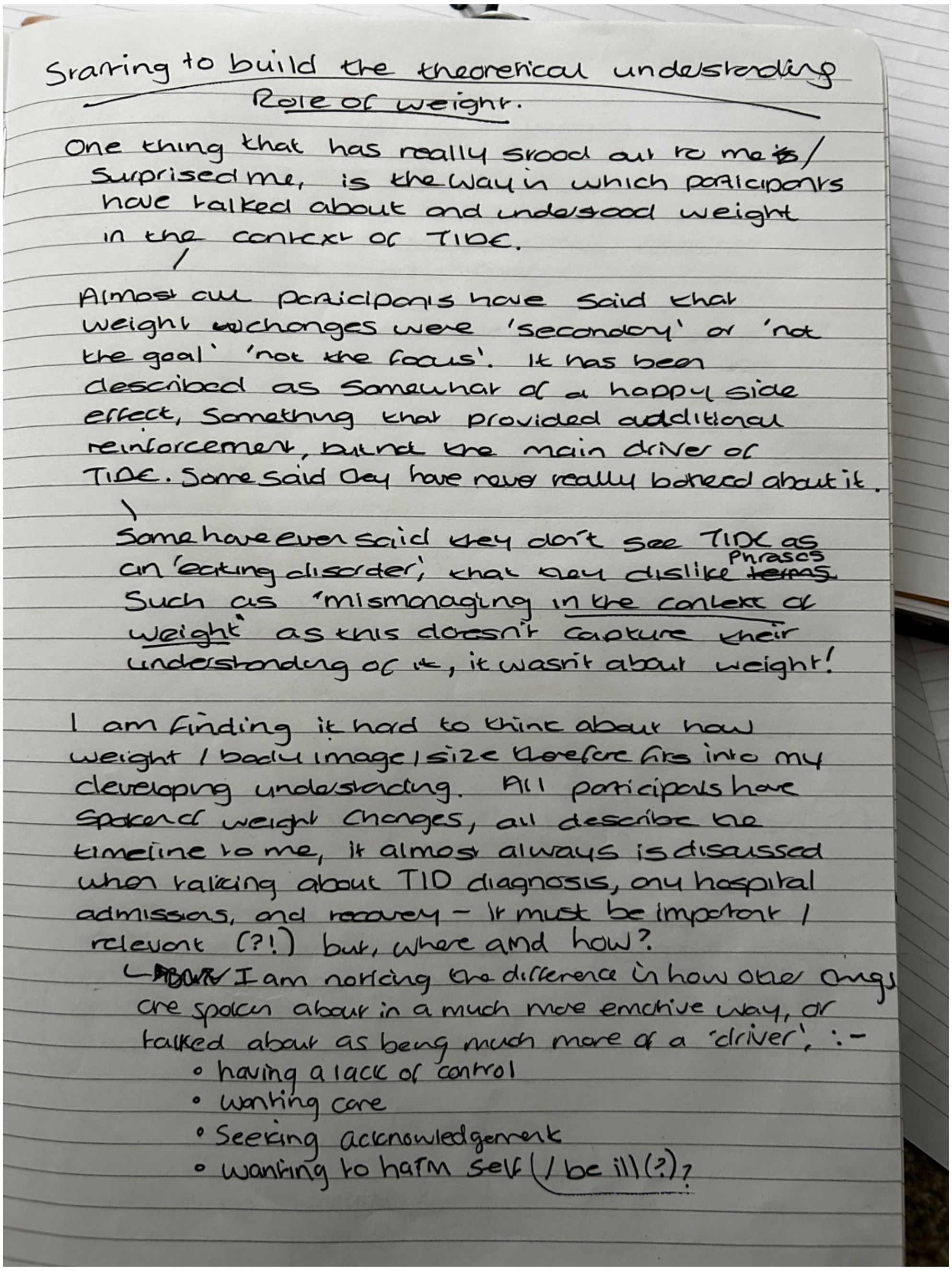
So far I have interviewed one male participant and all others have been female - I remember during the interview, and in my reflections afterwards, I initially felt that his experiences seemed quite different and separate to the other participants I had heard from - I wasn't sure how or if ~~that~~ the experiences would connect to those expressed by others.

↓.

I have put out a recruitment note aimed specifically at men to further try to hear from a male perspective... one has expressed interest and I am hopeful that this will further develop the understanding that I am constructing.

However, I have also noticed during my initial analysis and very early draft of connecting concepts together, that his experiences are actually very connected to those told by others - whilst the behaviours and ~~presentation~~ forms of disordered eating differed, I can really see how some of the underlying cycles and functions that he seemed to describe connect nicely with those described by others.

- It seems that a similar thing may be happening, but presented in a different way (?).



Starting to build the theoretical understanding

Role of weight.

One thing that has really stood out to me ~~is~~/ surprised me, is the way in which participants have talked about and understood weight in the context of T1DE.

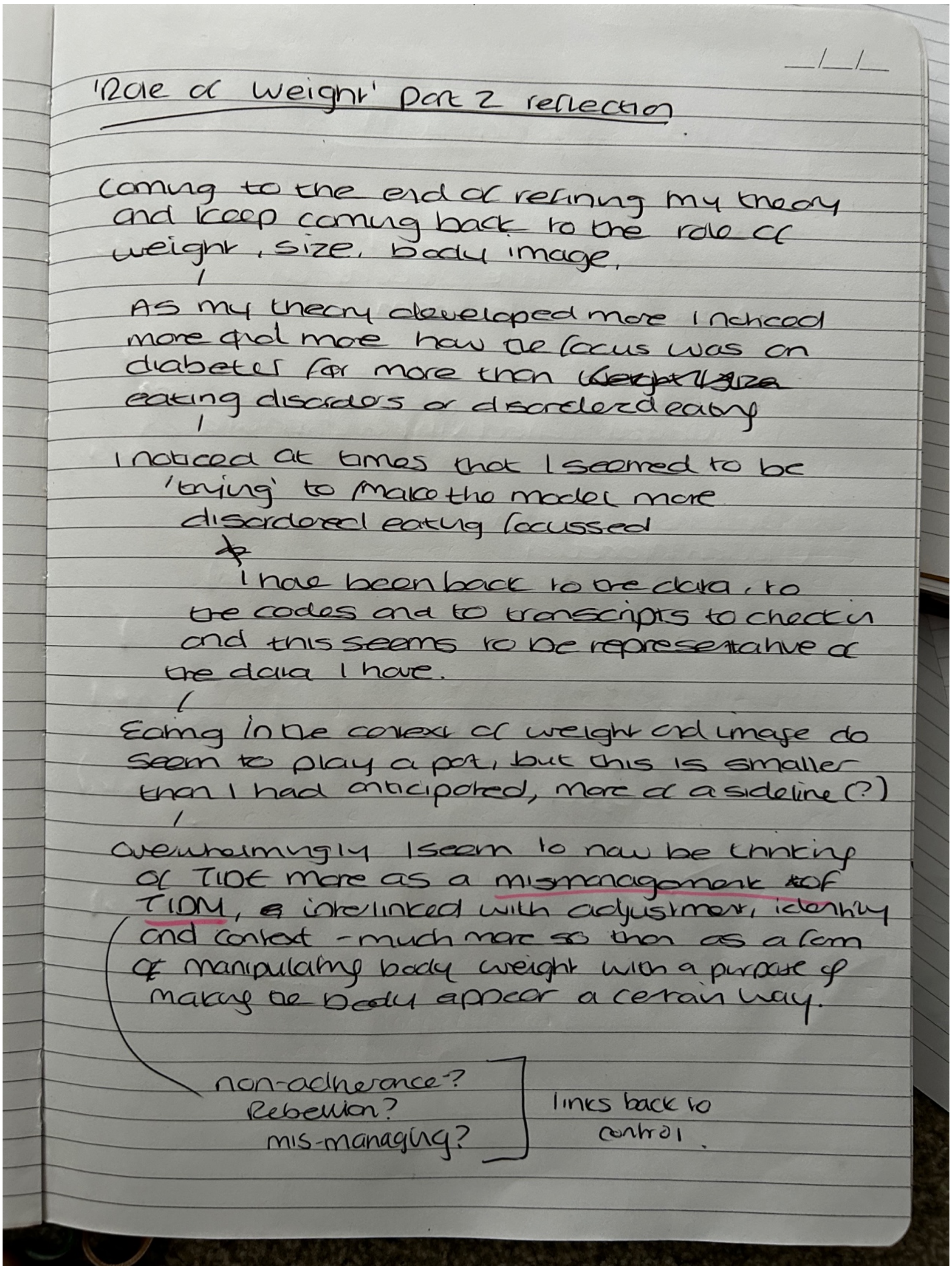
Almost all participants have said that weight changes were 'secondary' or 'not the goal' 'not the focus'. It has been described as somewhat of a happy side effect, something that provided additional reinforcement, but not the main driver of T1DE. Some said they have never really bothered about it.

Some have even said they don't see T1DE as an 'eating disorder', that they dislike ~~terms~~ phrases such as 'mismanaging in the context of weight' as this doesn't capture their understanding of it, it wasn't about weight!

I am finding it hard to think about how weight / body image / size therefore fits into my developing understanding. All participants have spoken of weight changes, all describe the timeline to me, it almost always is discussed when talking about T1D diagnosis, any hospital admissions, and recovery – it must be important / relevant (?!) but, where and how?

↳ I am noticing the difference in how other things are spoken about in a much more emotive way, or talked about as being much more of a 'driver', :-

- having a lack of control
- wanting care
- Seeking acknowledgement
- wanting to harm self (/ be ill (?))?



__/__/__

'Role of Weight' part 2 reflection

Coming to the end of refining my theory and keep coming back to the role of weight, size, body image.

/

As my theory developed more I noticed more and more how the focus was on diabetes far more than ~~weight/size~~ eating disorders or disordered eating

/

I noticed at times that I seemed to be 'trying' to make the model more disordered eating focussed

&

I have been back to the data, to the codes and to transcripts to check in and this seems to be representative of the data I have.

/

Eating in the context of weight and image do seem to play a part, but this is smaller than I had anticipated, more of a sideline (?)

/

Overwhelmingly I seem to now be thinking of T1DE more as a mismanagement ~~&~~ of T1DM, ~~&~~ interlinked with adjustment, identity and context - much more so than as a form of manipulating body weight with a purpose of making the body appear a certain way.

non-adherence?
Rebellion?
mis-managing?

links back to control.

Appendix B: SLR extraction table

From Li et al., (2019). Collecting data. *Cochrane handbook for systematic reviews of interventions*, 109-141.

Information about data extraction from reports

Name of data extractors, date of data extraction, and identification features of each report from which data are being extracted

Eligibility criteria

Confirm eligibility of the study for the review

Study methods

Study design:

Recruitment and sampling procedures used (including at the level of individual participants and clusters/sites if relevant)

Enrolment start and end dates; length of participant follow-up

Methods used to prevent and address missing data*

Statistical analysis:

Unit of analysis (e.g. individual participant, clinic, village, body part)

Statistical methods used if computed effect estimates are extracted from reports, including any covariates included in the statistical model

Likelihood of reporting and other biases*

Source(s) of funding or other material support for the study

Authors’ financial relationship and other potential conflicts of interest

Participants

Setting

Region(s) and country/countries from which study participants were recruited

Study eligibility criteria, including diagnostic criteria

Characteristics of participants at the beginning (or baseline) of the study (e.g. age, sex, comorbidity, socio-economic status)

Intervention

Description of the intervention(s) and comparison intervention(s), ideally with sufficient detail for replication:

- Components, routes of delivery, doses, timing, frequency, intervention protocols, length of intervention
- Factors relevant to implementation (e.g. staff qualifications, equipment requirements)
- Integrity of interventions (i.e. the degree to which specified procedures or components of the intervention were implemented as planned)
- Description of co-interventions
- Definition of ‘control’ groups (e.g. no intervention, placebo, minimally active comparator, or components of usual care)
- Components, dose, timing, frequency
- For observational studies: description of how intervention status was assessed; length of exposure, cumulative exposure

Outcomes

For each pre-specified outcome domain (e.g. anxiety) in the systematic review:

- Whether there is evidence that the outcome domain was assessed (especially important if the outcome was assessed but the results not presented; see Chapter 13)
- Measurement tool or instrument (including definition of clinical outcomes or endpoints); for a scale, name of the scale (e.g. the Hamilton Anxiety Rating Scale), upper and lower limits, and whether a high or low score is favourable, definitions of any thresholds if appropriate
- Specific metric (e.g. post-intervention anxiety, or change in anxiety from baseline to a post-intervention time point, or post-intervention presence of anxiety (yes/no))
- Method of aggregation (e.g. mean and standard deviation of anxiety scores in each group, or proportion of people with anxiety)
- Timing of outcome measurements (e.g. assessments at end of eight-week intervention period, events occurring during the eight-week intervention period)
- Adverse outcomes need special attention depending on whether they are collected systematically or non-systematically (e.g. by voluntary report)

Results

For each group, and for each outcome at each time point: number of participants randomly assigned and included in the analysis; and number of participants who withdrew, were lost to follow-up or were excluded (with reasons for each)

Summary data for each group (e.g. 2×2 table for dichotomous data; means and standard deviations for continuous data)

Between-group estimates that quantify the effect of the intervention on the outcome, and their precision (e.g. risk ratio, odds ratio, mean difference)

If subgroup analysis is planned, the same information would need to be extracted for each participant subgroup

Miscellaneous

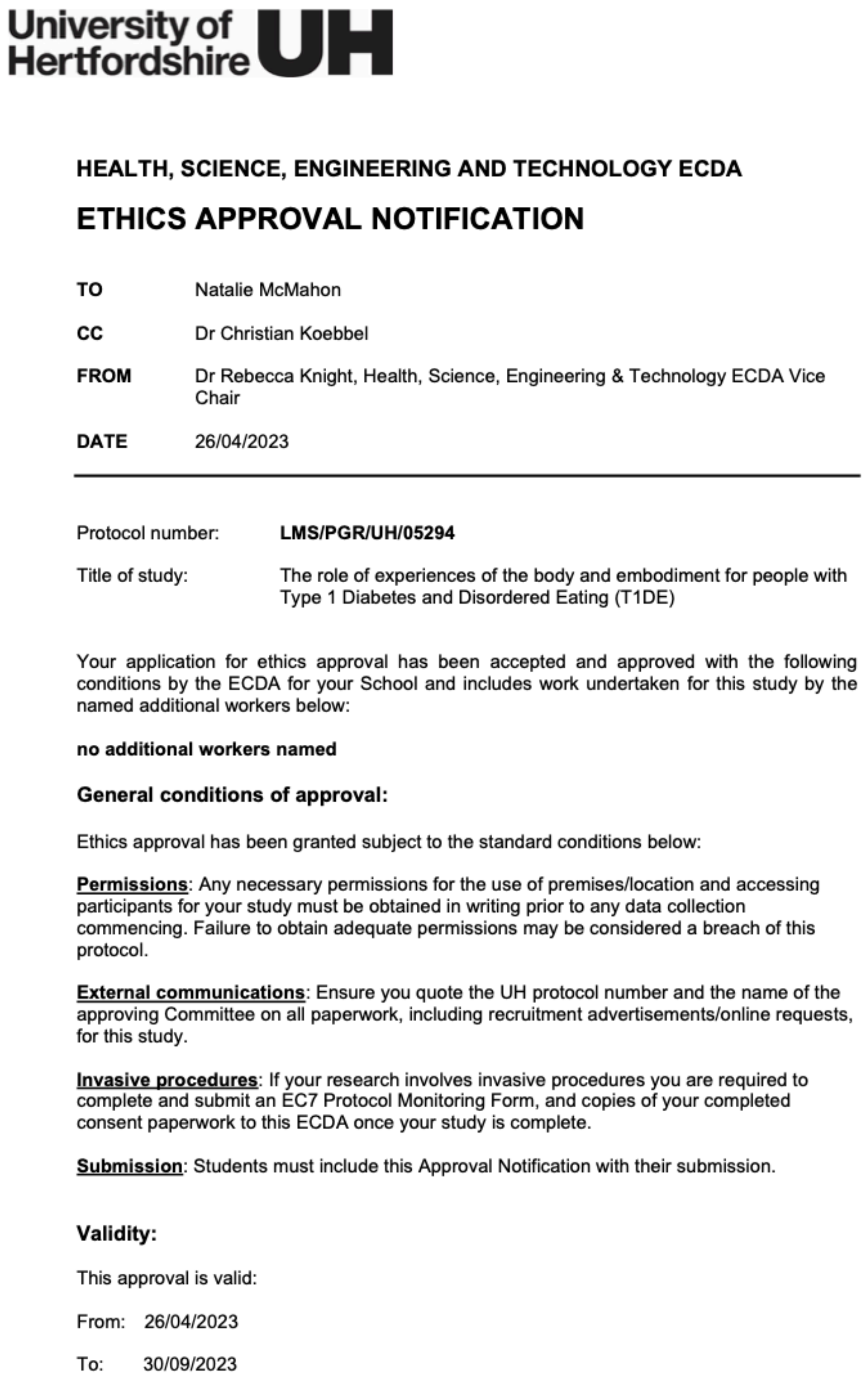
Key conclusions of the study authors

Reference to other relevant studies

Correspondence required

Miscellaneous comments from the study authors or by the review authors

Appendix C: Proof of ethical approval



University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO Natalie McMahon

CC Dr Christian Koebbel

FROM Dr Rebecca Knight, Health, Science, Engineering & Technology ECDA Vice Chair

DATE 26/04/2023

Protocol number: **LMS/PGR/UH/05294**

Title of study: The role of experiences of the body and embodiment for people with Type 1 Diabetes and Disordered Eating (T1DE)

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

no additional workers named

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

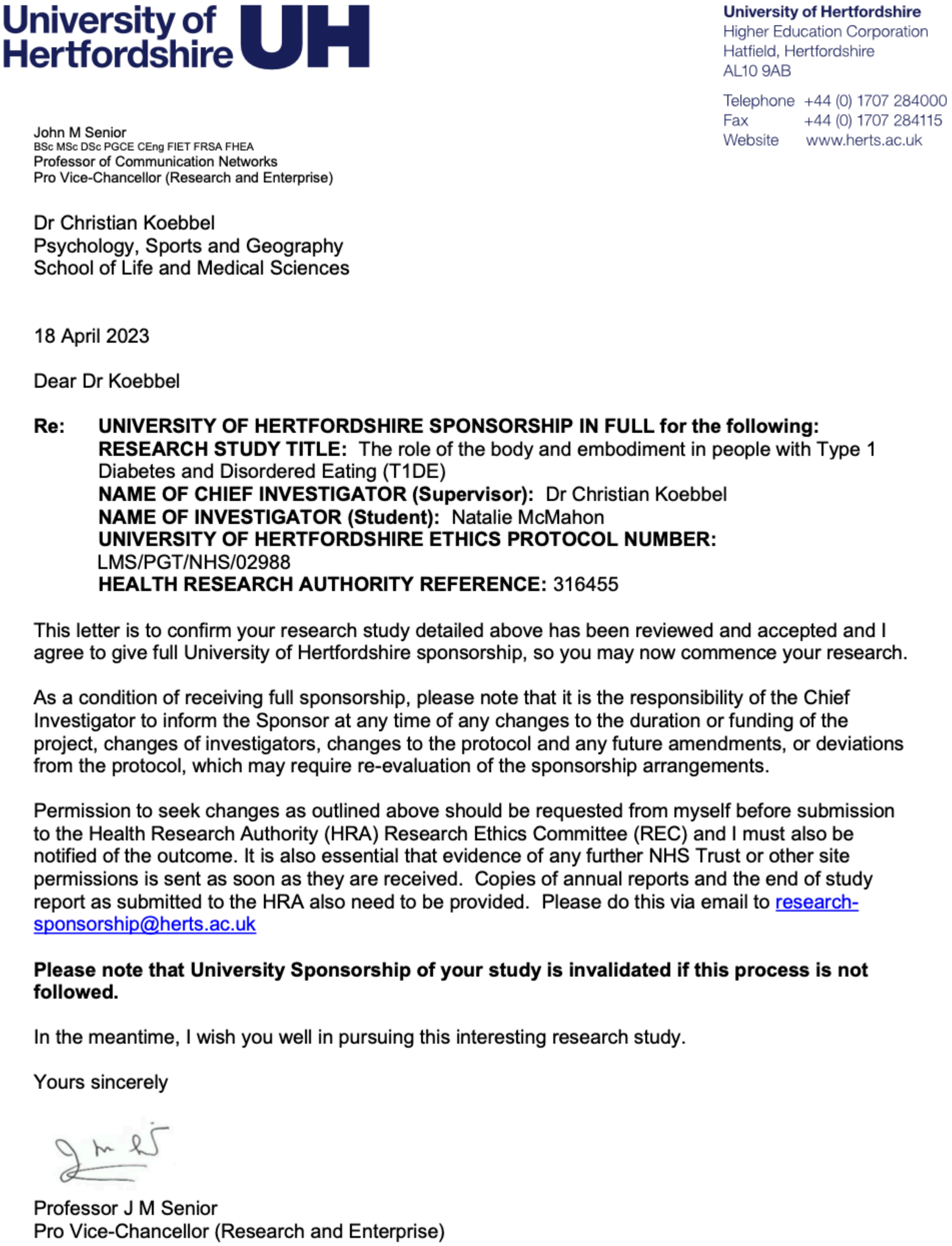
Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 26/04/2023

To: 30/09/2023



University of Hertfordshire
Higher Education Corporation
Hatfield, Hertfordshire
AL10 9AB

Telephone +44 (0) 1707 284000
Fax +44 (0) 1707 284115
Website www.herts.ac.uk

John M Senior
BSc MSc DSc PGCE CEng FIET FRSA FHEA
Professor of Communication Networks
Pro Vice-Chancellor (Research and Enterprise)

Dr Christian Koebbel
Psychology, Sports and Geography
School of Life and Medical Sciences

18 April 2023

Dear Dr Koebbel

Re: **UNIVERSITY OF HERTFORDSHIRE SPONSORSHIP IN FULL for the following:**
RESEARCH STUDY TITLE: The role of the body and embodiment in people with Type 1 Diabetes and Disordered Eating (T1DE)
NAME OF CHIEF INVESTIGATOR (Supervisor): Dr Christian Koebbel
NAME OF INVESTIGATOR (Student): Natalie McMahon
UNIVERSITY OF HERTFORDSHIRE ETHICS PROTOCOL NUMBER: LMS/PGT/NHS/02988
HEALTH RESEARCH AUTHORITY REFERENCE: 316455

This letter is to confirm your research study detailed above has been reviewed and accepted and I agree to give full University of Hertfordshire sponsorship, so you may now commence your research.

As a condition of receiving full sponsorship, please note that it is the responsibility of the Chief Investigator to inform the Sponsor at any time of any changes to the duration or funding of the project, changes of investigators, changes to the protocol and any future amendments, or deviations from the protocol, which may require re-evaluation of the sponsorship arrangements.

Permission to seek changes as outlined above should be requested from myself before submission to the Health Research Authority (HRA) Research Ethics Committee (REC) and I must also be notified of the outcome. It is also essential that evidence of any further NHS Trust or other site permissions is sent as soon as they are received. Copies of annual reports and the end of study report as submitted to the HRA also need to be provided. Please do this via email to research-sponsorship@herts.ac.uk

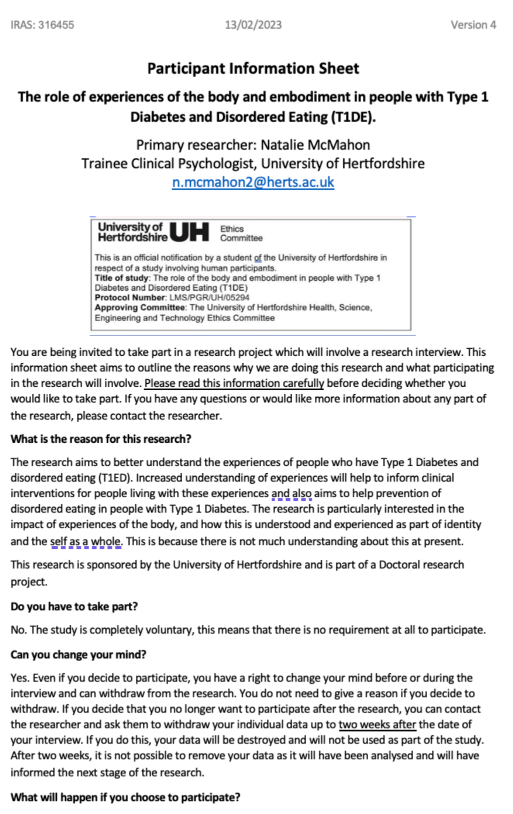
Please note that University Sponsorship of your study is invalidated if this process is not followed.

In the meantime, I wish you well in pursuing this interesting research study.

Yours sincerely

Professor J M Senior
Pro Vice-Chancellor (Research and Enterprise)

Appendix D: Participant Information Sheet



IRAS: 316455 13/02/2023 Version 4

Participant Information Sheet

The role of experiences of the body and embodiment in people with Type 1 Diabetes and Disordered Eating (T1DE).

Primary researcher: Natalie McMahon
Trainee Clinical Psychologist, University of Hertfordshire
n.mcmahon2@herts.ac.uk

University of Hertfordshire UH Ethics Committee

This is an official notification by a student of the University of Hertfordshire in respect of a study involving human participants.
Title of study: The role of the body and embodiment in people with Type 1 Diabetes and Disordered Eating (T1DE)
Protocol Number: LMS/PGR/UH/05294
Approving Committee: The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee

You are being invited to take part in a research project which will involve a research interview. This information sheet aims to outline the reasons why we are doing this research and what participating in the research will involve. Please read this information carefully before deciding whether you would like to take part. If you have any questions or would like more information about any part of the research, please contact the researcher.

What is the reason for this research?

The research aims to better understand the experiences of people who have Type 1 Diabetes and disordered eating (T1ED). Increased understanding of experiences will help to inform clinical interventions for people living with these experiences and also aims to help prevention of disordered eating in people with Type 1 Diabetes. The research is particularly interested in the impact of experiences of the body, and how this is understood and experienced as part of identity and the self as a whole. This is because there is not much understanding about this at present.

This research is sponsored by the University of Hertfordshire and is part of a Doctoral research project.

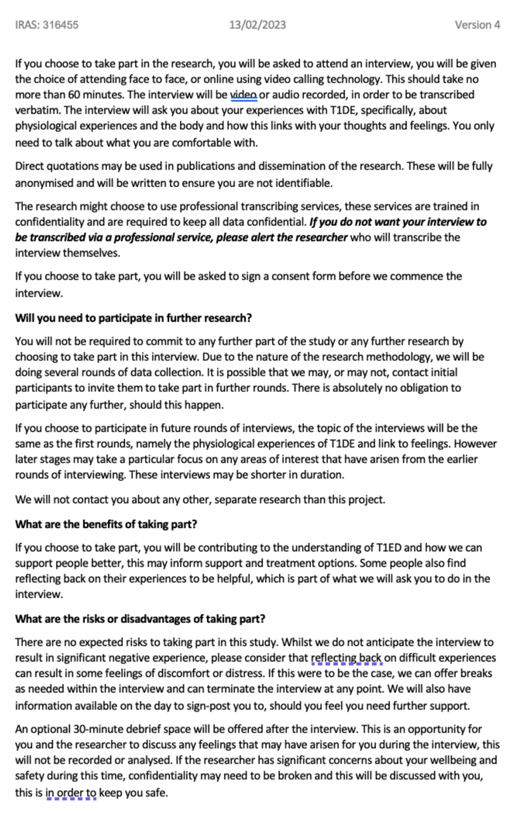
Do you have to take part?

No. The study is completely voluntary, this means that there is no requirement at all to participate.

Can you change your mind?

Yes. Even if you decide to participate, you have a right to change your mind before or during the interview and can withdraw from the research. You do not need to give a reason if you decide to withdraw. If you decide that you no longer want to participate after the research, you can contact the researcher and ask them to withdraw your individual data up to two weeks after the date of your interview. If you do this, your data will be destroyed and will not be used as part of the study. After two weeks, it is not possible to remove your data as it will have been analysed and will have informed the next stage of the research.

What will happen if you choose to participate?



IRAS: 316455 13/02/2023 Version 4

If you choose to take part in the research, you will be asked to attend an interview, you will be given the choice of attending face to face, or online using video calling technology. This should take no more than 60 minutes. The interview will be video or audio recorded, in order to be transcribed verbatim. The interview will ask you about your experiences with T1DE, specifically, about physiological experiences and the body and how this links with your thoughts and feelings. You only need to talk about what you are comfortable with.

Direct quotations may be used in publications and dissemination of the research. These will be fully anonymised and will be written to ensure you are not identifiable.

The research might choose to use professional transcribing services, these services are trained in confidentiality and are required to keep all data confidential. ***If you do not want your interview to be transcribed via a professional service, please alert the researcher*** who will transcribe the interview themselves.

If you choose to take part, you will be asked to sign a consent form before we commence the interview.

Will you need to participate in further research?

You will not be required to commit to any further part of the study or any further research by choosing to take part in this interview. Due to the nature of the research methodology, we will be doing several rounds of data collection. It is possible that we may, or may not, contact initial participants to invite them to take part in further rounds. There is absolutely no obligation to participate any further, should this happen.

If you choose to participate in future rounds of interviews, the topic of the interviews will be the same as the first rounds, namely the physiological experiences of T1DE and link to feelings. However later stages may take a particular focus on any areas of interest that have arisen from the earlier rounds of interviewing. These interviews may be shorter in duration.

We will not contact you about any other, separate research than this project.

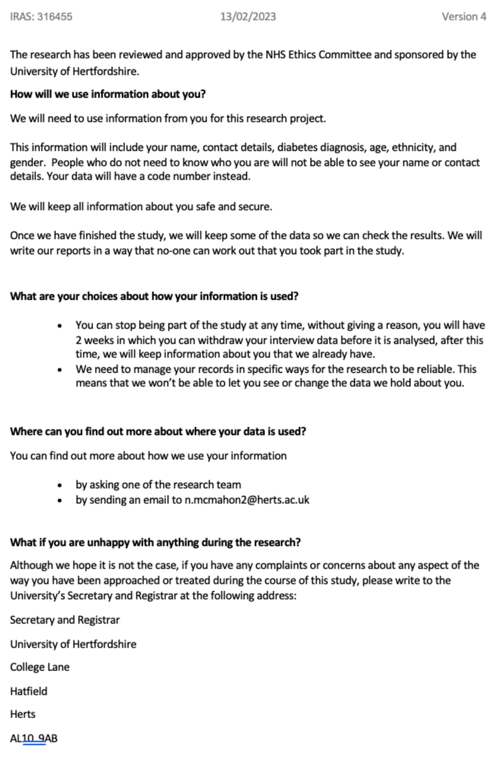
What are the benefits of taking part?

If you choose to take part, you will be contributing to the understanding of T1ED and how we can support people better, this may inform support and treatment options. Some people also find reflecting back on their experiences to be helpful, which is part of what we will ask you to do in the interview.

What are the risks or disadvantages of taking part?

There are no expected risks to taking part in this study. Whilst we do not anticipate the interview to result in significant negative experience, please consider that reflecting back on difficult experiences can result in some feelings of discomfort or distress. If this were to be the case, we can offer breaks as needed within the interview and can terminate the interview at any point. We will also have information available on the day to sign-post you to, should you feel you need further support.

An optional 30-minute debrief space will be offered after the interview. This is an opportunity for you and the researcher to discuss any feelings that may have arisen for you during the interview, this will not be recorded or analysed. If the researcher has significant concerns about your wellbeing and safety during this time, confidentiality may need to be broken and this will be discussed with you, this is in order to keep you safe.



IRAS: 316455 13/02/2023 Version 4

The research has been reviewed and approved by the NHS Ethics Committee and sponsored by the University of Hertfordshire.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your name, contact details, diabetes diagnosis, age, ethnicity, and gender. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, you will have 2 weeks in which you can withdraw your interview data before it is analysed, after this time, we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about where your data is used?

You can find out more about how we use your information

- by asking one of the research team
- by sending an email to n.mcmahon2@herts.ac.uk

What if you are unhappy with anything during the research?

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar

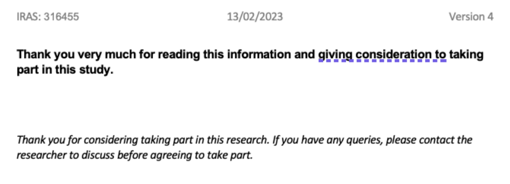
University of Hertfordshire

College Lane

Hatfield

Herts

AL10 9AB

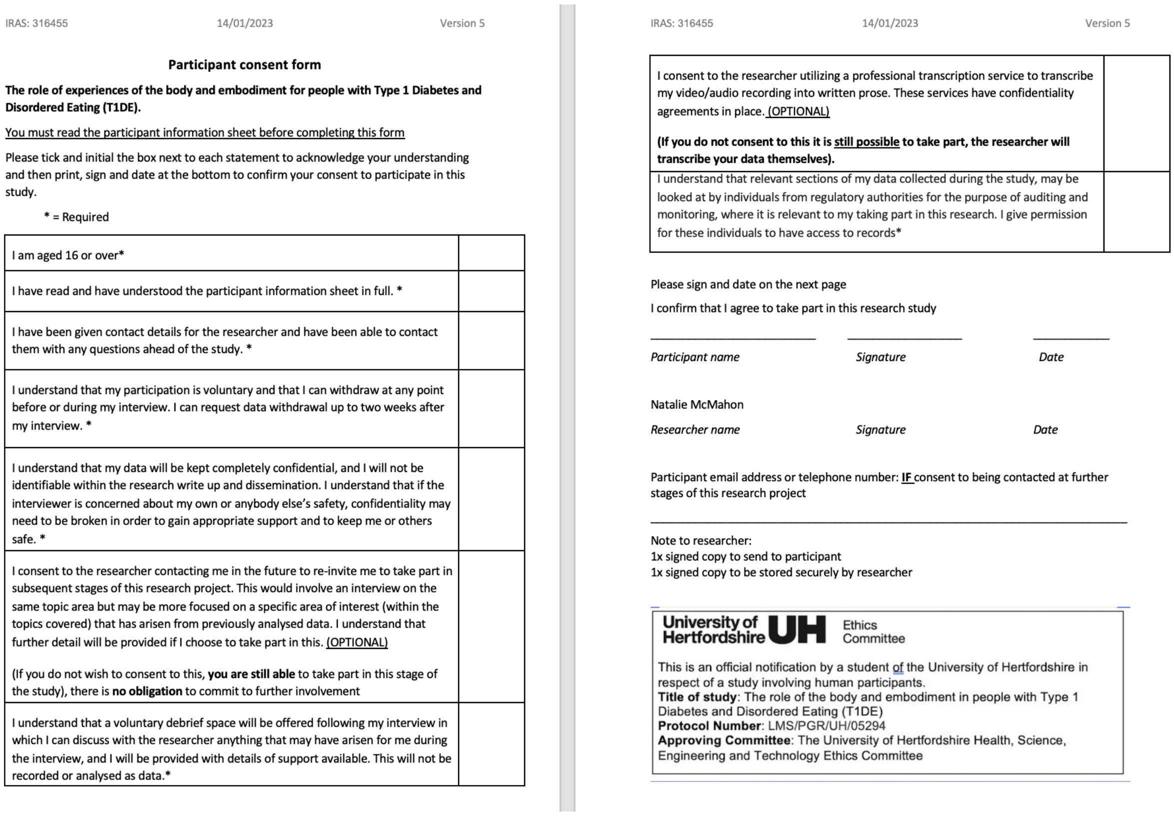


IRAS: 316455 13/02/2023 Version 4

Thank you very much for reading this information and giving consideration to taking part in this study.

Thank you for considering taking part in this research. If you have any queries, please contact the researcher to discuss before agreeing to take part.

Appendix E: Participant consent form



IRAS: 316455 14/01/2023 Version 5

Participant consent form

The role of experiences of the body and embodiment for people with Type 1 Diabetes and Disordered Eating (T1DE).

You must read the participant information sheet before completing this form

Please tick and initial the box next to each statement to acknowledge your understanding and then print, sign and date at the bottom to confirm your consent to participate in this study.

* = Required

I am aged 16 or over*	
I have read and have understood the participant information sheet in full. *	
I have been given contact details for the researcher and have been able to contact them with any questions ahead of the study. *	
I understand that my participation is voluntary and that I can withdraw at any point before or during my interview. I can request data withdrawal up to two weeks after my interview. *	
I understand that my data will be kept completely confidential, and I will not be identifiable within the research write up and dissemination. I understand that if the interviewer is concerned about my own or anybody else's safety, confidentiality may need to be broken in order to gain appropriate support and to keep me or others safe. *	
I consent to the researcher contacting me in the future to re-invite me to take part in subsequent stages of this research project. This would involve an interview on the same topic area but may be more focused on a specific area of interest (within the topics covered) that has arisen from previously analysed data. I understand that further detail will be provided if I choose to take part in this. (OPTIONAL) (If you do not wish to consent to this, **you are still able** to take part in this stage of the study), there is **no obligation** to commit to further involvement	
I understand that a voluntary debrief space will be offered following my interview in which I can discuss with the researcher anything that may have arisen for me during the interview, and I will be provided with details of support available. This will not be recorded or analysed as data.*	

IRAS: 316455 14/01/2023 Version 5

I consent to the researcher utilizing a professional transcription service to transcribe my video/audio recording into written prose. These services have confidentiality agreements in place. (OPTIONAL) **(If you do not consent to this it is still possible to take part, the researcher will transcribe your data themselves).**	
I understand that relevant sections of my data collected during the study, may be looked at by individuals from regulatory authorities for the purpose of auditing and monitoring, where it is relevant to my taking part in this research. I give permission for these individuals to have access to records*	

Please sign and date on the next page

I confirm that I agree to take part in this research study

________________ ________________ __________

Participant name *Signature* *Date*

Natalie McMahon

Researcher name *Signature* *Date*

Participant email address or telephone number: **IF** consent to being contacted at further stages of this research project

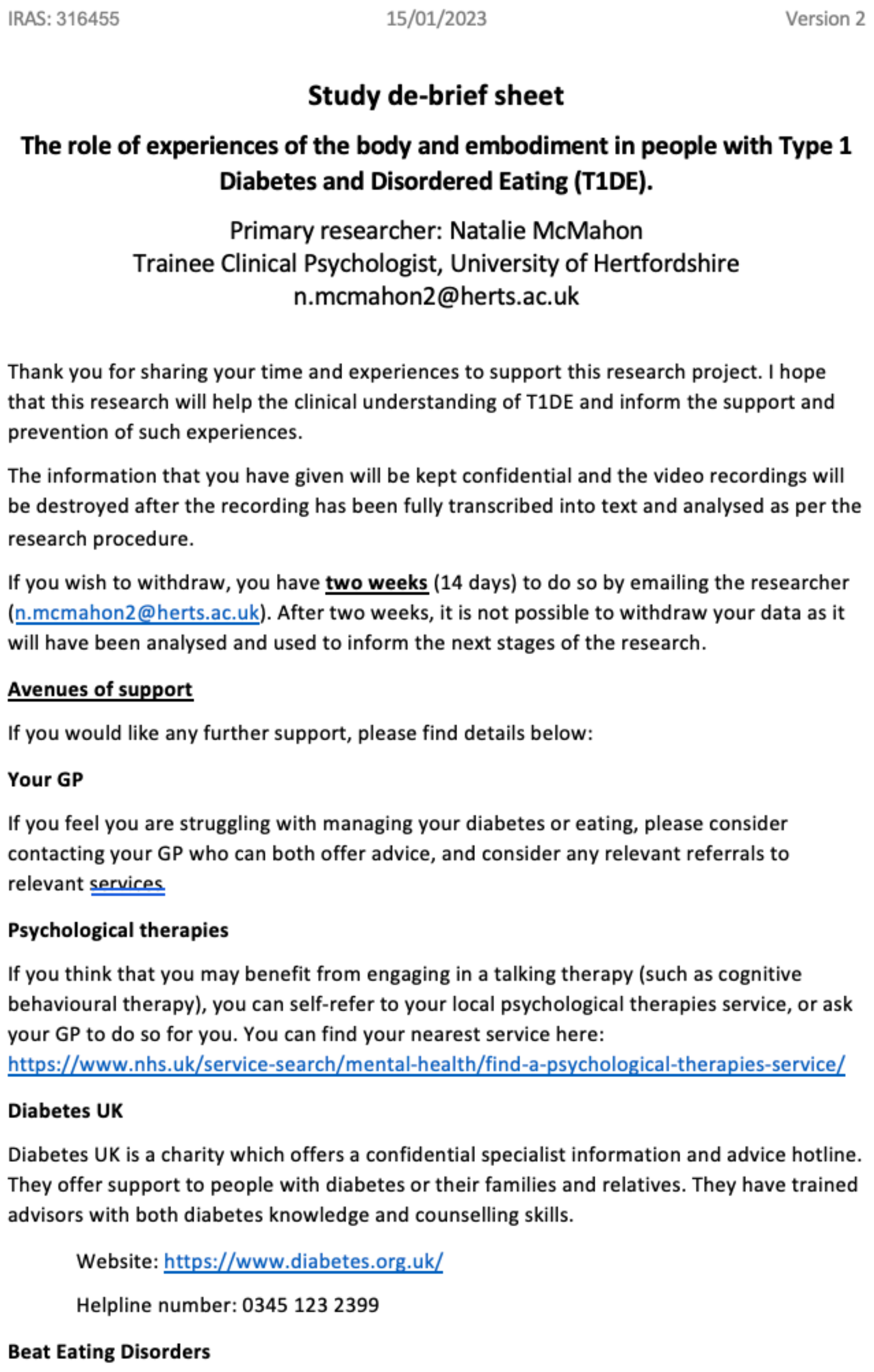
____

Note to researcher:
1x signed copy to send to participant
1x signed copy to be stored securely by researcher

University of Hertfordshire UH Ethics Committee

This is an official notification by a student of the University of Hertfordshire in respect of a study involving human participants.
Title of study: The role of the body and embodiment in people with Type 1 Diabetes and Disordered Eating (T1DE)
Protocol Number: LMS/PGR/UH/05294
Approving Committee: The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee

Appendix F: Participant Debrief sheet



IRAS: 316455 15/01/2023 Version 2

Study de-brief sheet

The role of experiences of the body and embodiment in people with Type 1 Diabetes and Disordered Eating (T1DE).

Primary researcher: Natalie McMahon
Trainee Clinical Psychologist, University of Hertfordshire
n.mcmahon2@herts.ac.uk

Thank you for sharing your time and experiences to support this research project. I hope that this research will help the clinical understanding of T1DE and inform the support and prevention of such experiences.

The information that you have given will be kept confidential and the video recordings will be destroyed after the recording has been fully transcribed into text and analysed as per the research procedure.

If you wish to withdraw, you have **two weeks** (14 days) to do so by emailing the researcher (n.mcmahon2@herts.ac.uk). After two weeks, it is not possible to withdraw your data as it will have been analysed and used to inform the next stages of the research.

Avenues of support

If you would like any further support, please find details below:

Your GP

If you feel you are struggling with managing your diabetes or eating, please consider contacting your GP who can both offer advice, and consider any relevant referrals to relevant services

Psychological therapies

If you think that you may benefit from engaging in a talking therapy (such as cognitive behavioural therapy), you can self-refer to your local psychological therapies service, or ask your GP to do so for you. You can find your nearest service here: https://www.nhs.uk/service-search/mental-health/find-a-psychological-therapies-service/

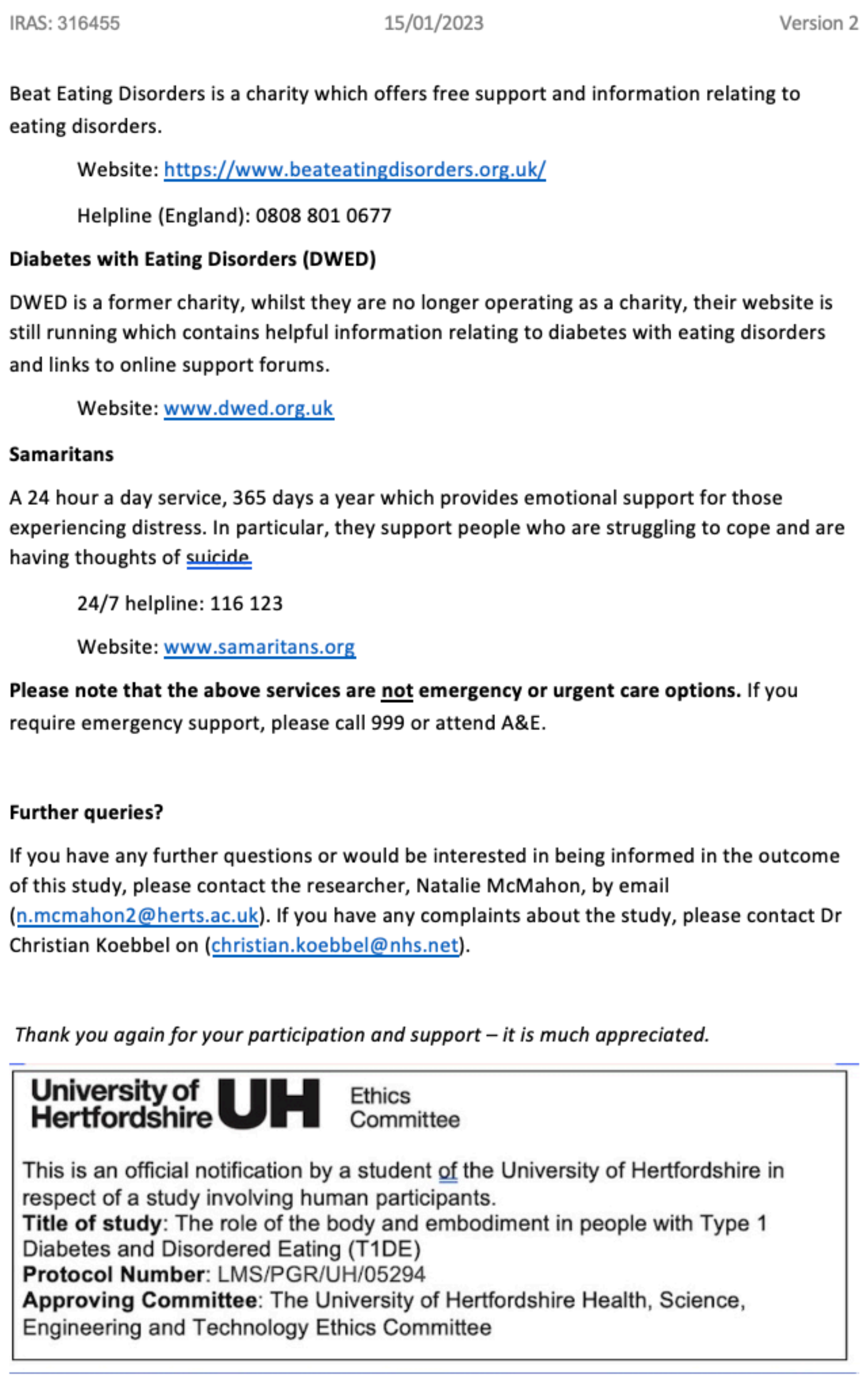
Diabetes UK

Diabetes UK is a charity which offers a confidential specialist information and advice hotline. They offer support to people with diabetes or their families and relatives. They have trained advisors with both diabetes knowledge and counselling skills.

Website: https://www.diabetes.org.uk/

Helpline number: 0345 123 2399

Beat Eating Disorders



Beat Eating Disorders is a charity which offers free support and information relating to eating disorders.

Website: https://www.beateatingdisorders.org.uk/

Helpline (England): 0808 801 0677

Diabetes with Eating Disorders (DWED)

DWED is a former charity, whilst they are no longer operating as a charity, their website is still running which contains helpful information relating to diabetes with eating disorders and links to online support forums.

Website: www.dwed.org.uk

Samaritans

A 24 hour a day service, 365 days a year which provides emotional support for those experiencing distress. In particular, they support people who are struggling to cope and are having thoughts of suicide.

24/7 helpline: 116 123

Website: www.samaritans.org

Please note that the above services are not emergency or urgent care options. If you require emergency support, please call 999 or attend A&E.

Further queries?

If you have any further questions or would be interested in being informed in the outcome of this study, please contact the researcher, Natalie McMahon, by email (n.mcmahon2@herts.ac.uk). If you have any complaints about the study, please contact Dr Christian Koebbel on (christian.koebbel@nhs.net).

Thank you again for your participation and support – it is much appreciated.

University of Hertfordshire UH
Ethics Committee

This is an official notification by a student of the University of Hertfordshire in respect of a study involving human participants.
Title of study: The role of the body and embodiment in people with Type 1 Diabetes and Disordered Eating (T1DE)
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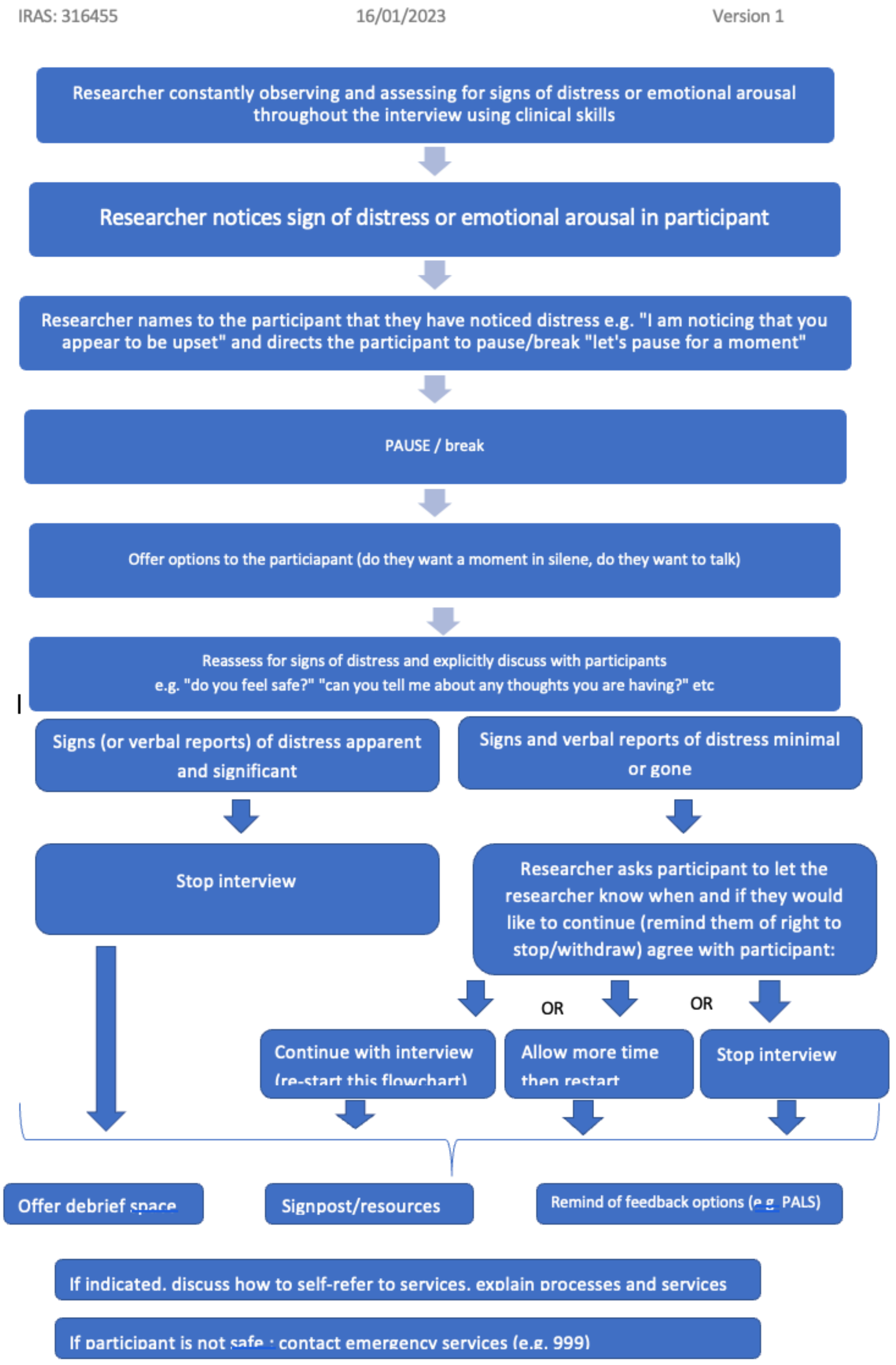
Appendix G: Interview distress protocol



IRAS: 316455 16/01/2023 Version 1

Researcher constantly observing and assessing for signs of distress or emotional arousal throughout the interview using clinical skills

Researcher notices sign of distress or emotional arousal in participant

Researcher names to the participant that they have noticed distress e.g. "I am noticing that you appear to be upset" and directs the participant to pause/break "let's pause for a moment"

PAUSE / break

Offer options to the particiapant (do they want a moment in silene, do they want to talk)

Reassess for signs of distress and explicitly discuss with participants
e.g. "do you feel safe?" "can you tell me about any thoughts you are having?" etc

Signs (or verbal reports) of distress apparent and significant

Signs and verbal reports of distress minimal or gone

Stop interview

Researcher asks participant to let the researcher know when and if they would like to continue (remind them of right to stop/withdraw) agree with participant:

Continue with interview (re-start this flowchart)

Allow more time then restart

Stop interview

Offer debrief space

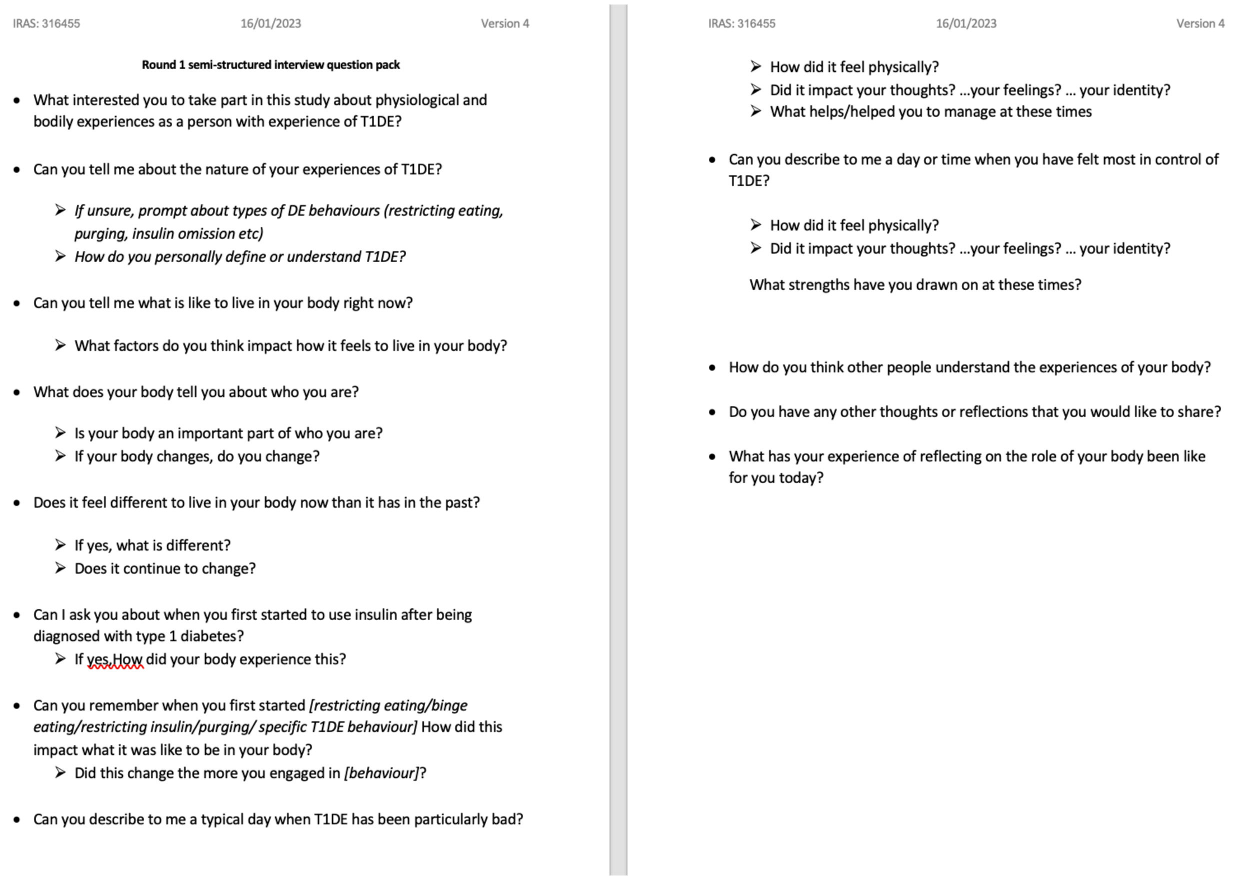
Signpost/resources

Remind of feedback options (e.g. PALS)

If indicated, discuss how to self-refer to services, explain processes and services

If participant is not safe : contact emergency services (e.g. 999)

Appendix H: Interview pack



IRAS: 316455 16/01/2023 Version 4

Round 1 semi-structured interview question pack

- What interested you to take part in this study about physiological and bodily experiences as a person with experience of T1DE?
- Can you tell me about the nature of your experiences of T1DE?
    - *If unsure, prompt about types of DE behaviours (restricting eating, purging, insulin omission etc)*
    - *How do you personally define or understand T1DE?*
- Can you tell me what is like to live in your body right now?
    - What factors do you think impact how it feels to live in your body?
- What does your body tell you about who you are?
    - Is your body an important part of who you are?
    - If your body changes, do you change?
- Does it feel different to live in your body now than it has in the past?
    - If yes, what is different?
    - Does it continue to change?
- Can I ask you about when you first started to use insulin after being diagnosed with type 1 diabetes?
    - If yes,How did your body experience this?
- Can you remember when you first started *[restricting eating/binge eating/restricting insulin/purging/ specific T1DE behaviour]* How did this impact what it was like to be in your body?
    - Did this change the more you engaged in *[behaviour]*?
- Can you describe to me a typical day when T1DE has been particularly bad?

IRAS: 316455 16/01/2023 Version 4

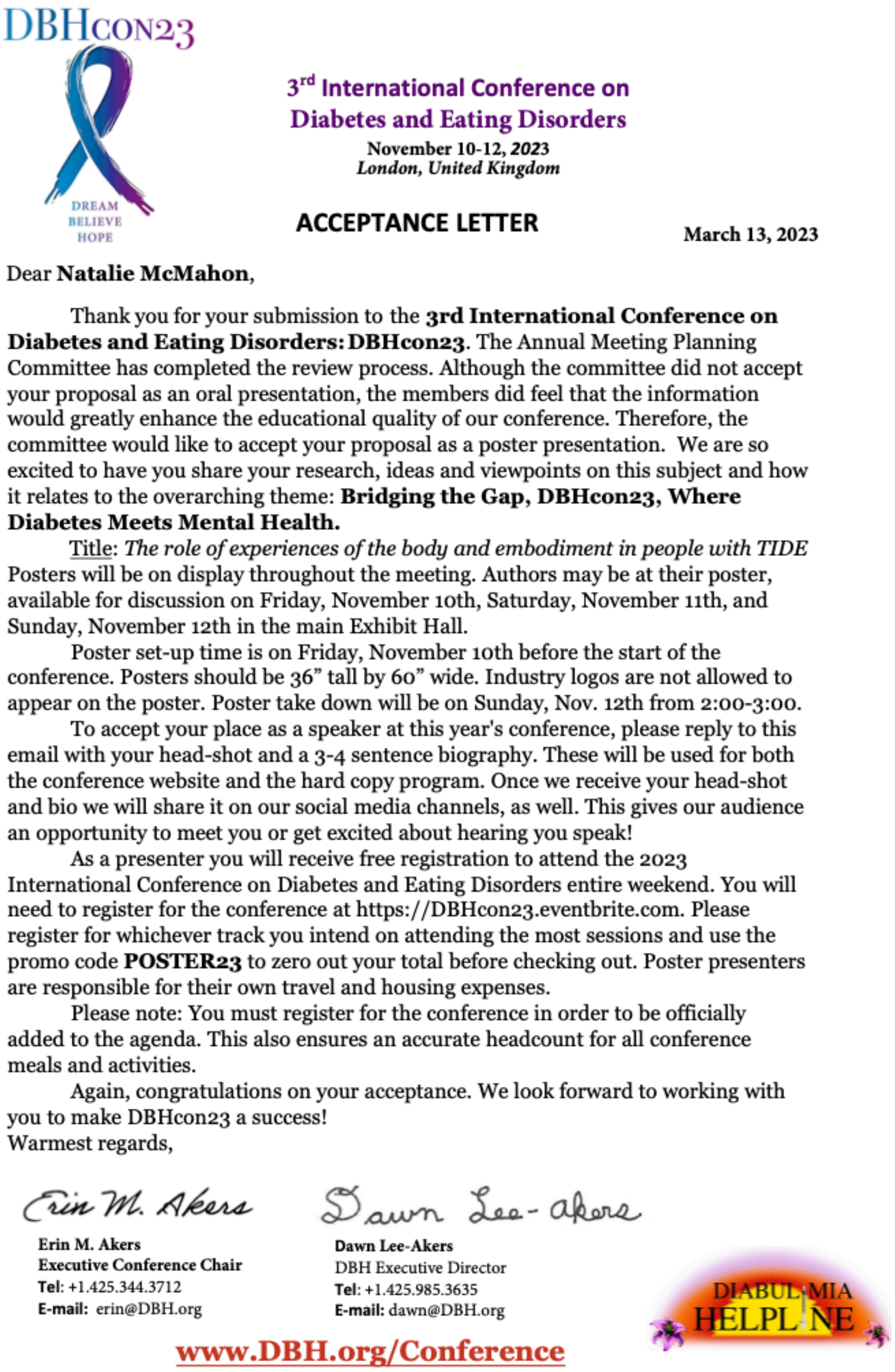
- How did it feel physically?
- Did it impact your thoughts? …your feelings? … your identity?
- What helps/helped you to manage at these times

- Can you describe to me a day or time when you have felt most in control of T1DE?
    - How did it feel physically?
    - Did it impact your thoughts? …your feelings? … your identity?

    What strengths have you drawn on at these times?

- How do you think other people understand the experiences of your body?
- Do you have any other thoughts or reflections that you would like to share?
- What has your experience of reflecting on the role of your body been like for you today?

Appendix I: Letter of acceptance for dissemination presentation



DBHcon23

DREAM
BELIEVE
HOPE

3rd International Conference on
Diabetes and Eating Disorders
November 10-12, *2023*
London, United Kingdom

ACCEPTANCE LETTER

March 13, 2023

Dear **Natalie McMahon**,

Thank you for your submission to the **3rd International Conference on Diabetes and Eating Disorders: DBHcon23**. The Annual Meeting Planning Committee has completed the review process. Although the committee did not accept your proposal as an oral presentation, the members did feel that the information would greatly enhance the educational quality of our conference. Therefore, the committee would like to accept your proposal as a poster presentation. We are so excited to have you share your research, ideas and viewpoints on this subject and how it relates to the overarching theme: **Bridging the Gap, DBHcon23, Where Diabetes Meets Mental Health.**

Title: *The role of experiences of the body and embodiment in people with TIDE*
Posters will be on display throughout the meeting. Authors may be at their poster, available for discussion on Friday, November 10th, Saturday, November 11th, and Sunday, November 12th in the main Exhibit Hall.

Poster set-up time is on Friday, November 10th before the start of the conference. Posters should be 36” tall by 60” wide. Industry logos are not allowed to appear on the poster. Poster take down will be on Sunday, Nov. 12th from 2:00-3:00.

To accept your place as a speaker at this year's conference, please reply to this email with your head-shot and a 3-4 sentence biography. These will be used for both the conference website and the hard copy program. Once we receive your head-shot and bio we will share it on our social media channels, as well. This gives our audience an opportunity to meet you or get excited about hearing you speak!

As a presenter you will receive free registration to attend the 2023 International Conference on Diabetes and Eating Disorders entire weekend. You will need to register for the conference at https://DBHcon23.eventbrite.com. Please register for whichever track you intend on attending the most sessions and use the promo code **POSTER23** to zero out your total before checking out. Poster presenters are responsible for their own travel and housing expenses.

Please note: You must register for the conference in order to be officially added to the agenda. This also ensures an accurate headcount for all conference meals and activities.

Again, congratulations on your acceptance. We look forward to working with you to make DBHcon23 a success!
Warmest regards,

Erin M. Akers

Erin M. Akers
Executive Conference Chair
Tel: +1.425.344.3712
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Dawn Lee-akers

Dawn Lee-Akers
DBH Executive Director
Tel: +1.425.985.3635
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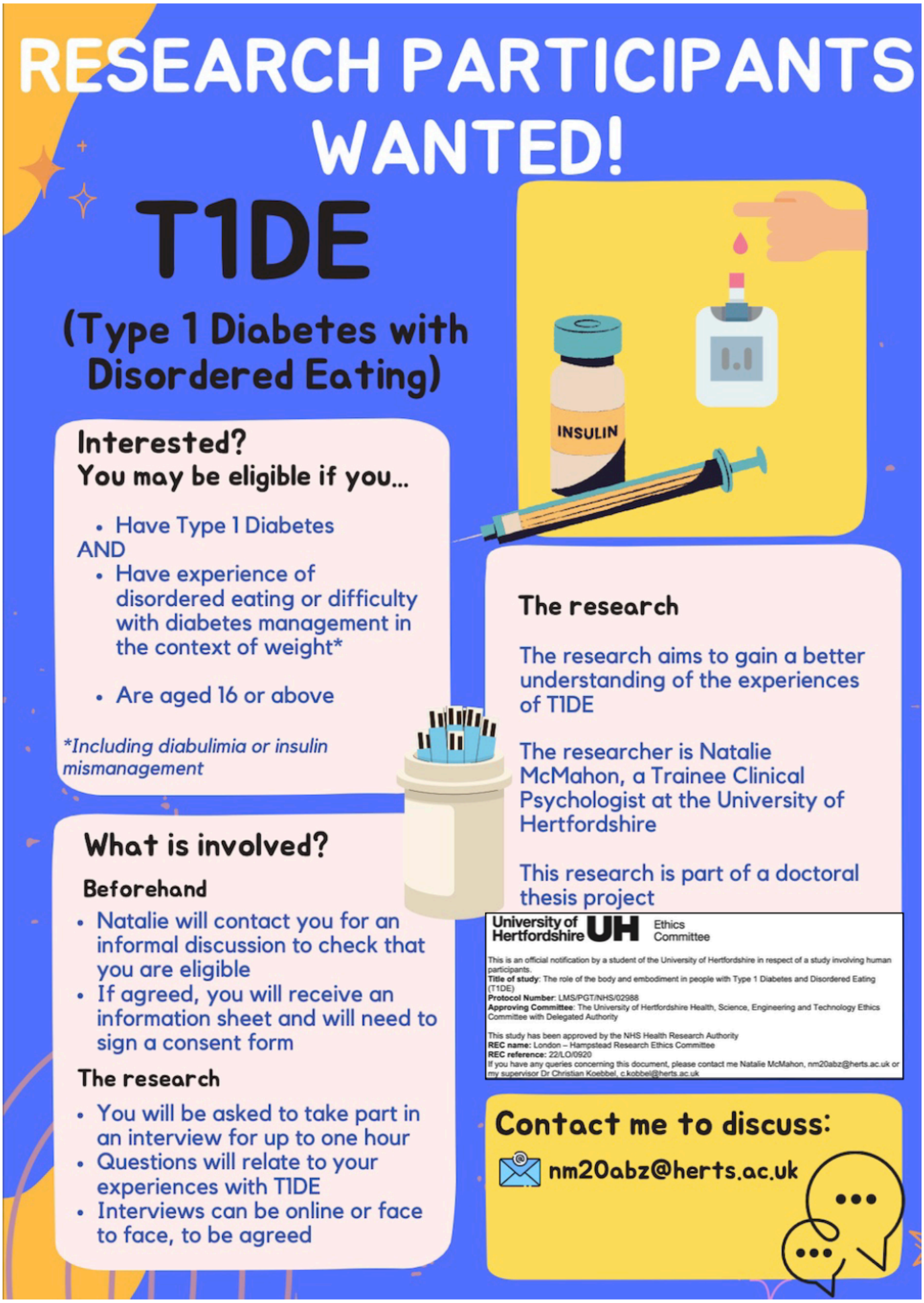
DIABULIMIA HELPLINE

www.DBH.org/Conference

Appendix J: Recruitment poster



RESEARCH PARTICIPANTS WANTED!

T1DE

(Type 1 Diabetes with Disordered Eating)

Interested?

You may be eligible if you…

- Have Type 1 Diabetes

AND

- Have experience of disordered eating or difficulty with diabetes management in the context of weight*
- Are aged 16 or above

**Including diabulimia or insulin mismanagement*

What is involved?

Beforehand

- Natalie will contact you for an informal discussion to check that you are eligible
- If agreed, you will receive an information sheet and will need to sign a consent form

The research

- You will be asked to take part in an interview for up to one hour
- Questions will relate to your experiences with T1DE
- Interviews can be online or face to face, to be agreed

The research

The research aims to gain a better understanding of the experiences of T1DE

The researcher is Natalie McMahon, a Trainee Clinical Psychologist at the University of Hertfordshire

This research is part of a doctoral thesis project

University of Hertfordshire UH Ethics Committee

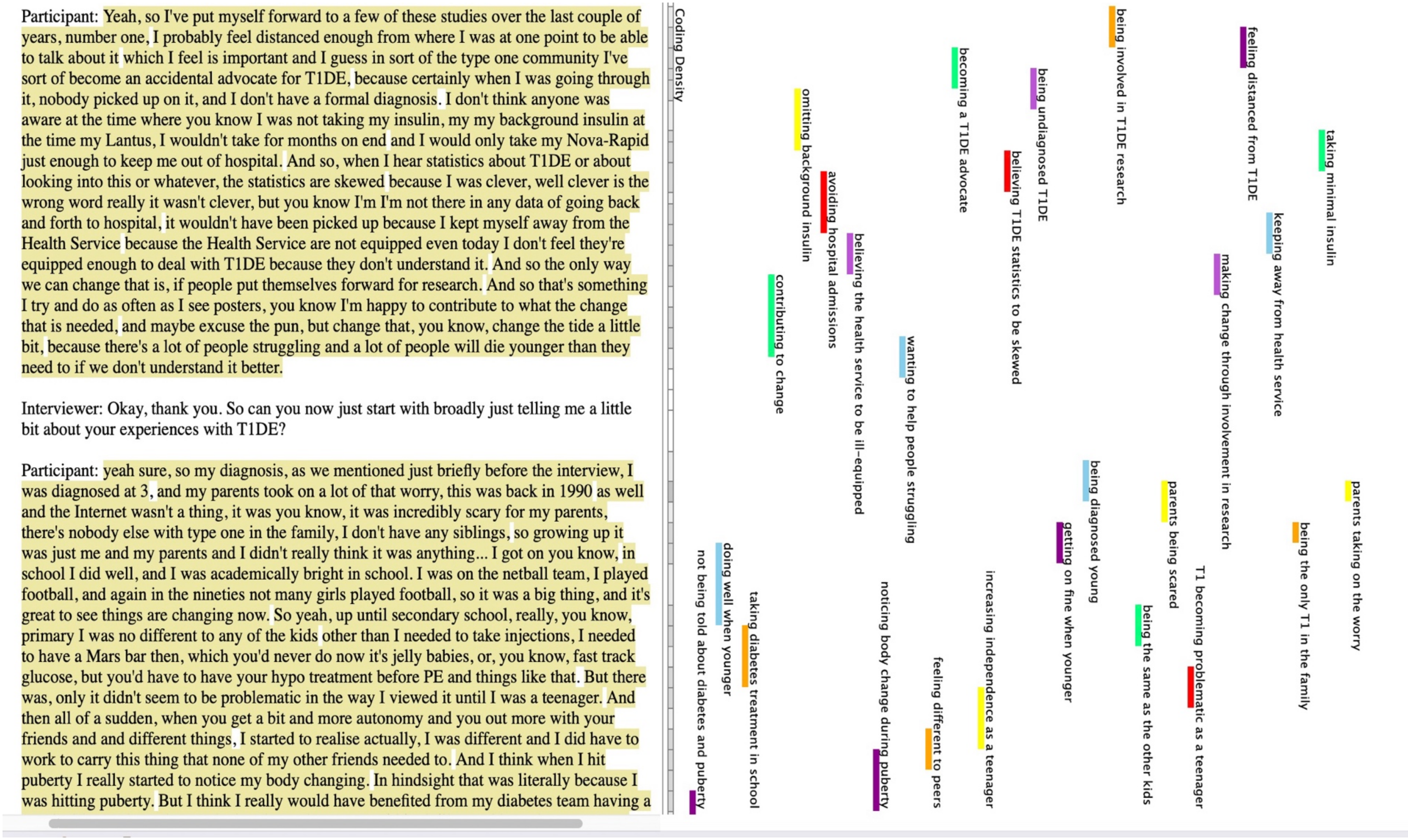
This is an official notification by a student of the University of Hertfordshire in respect of a study involving human participants.
Title of study: The role of the body and embodiment in people with Type 1 Diabetes and Disordered Eating (T1DE)
Protocol Number: LMS/PGT/NHS/02988
Approving Committee: The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

This study has been approved by the NHS Health Research Authority
REC name: London – Hampstead Research Ethics Committee
REC reference: 22/LO/0920
If you have any queries concerning this document, please contact me Natalie McMahon, nm20abz@herts.ac.uk or my supervisor Dr Christian Koebbel, c.kobbel@herts.ac.uk

Contact me to discuss:

nm20abz@herts.ac.uk

Appendix K: Analysis extracts: coding and finding categories



Participant: Yeah, so I've put myself forward to a few of these studies over the last couple of years, number one, I probably feel distanced enough from where I was at one point to be able to talk about it which I feel is important and I guess in sort of the type one community I've sort of become an accidental advocate for T1DE, because certainly when I was going through it, nobody picked up on it, and I don't have a formal diagnosis. I don't think anyone was aware at the time where you know I was not taking my insulin, my my background insulin at the time my Lantus, I wouldn't take for months on end and I would only take my Nova-Rapid just enough to keep me out of hospital. And so, when I hear statistics about T1DE or about looking into this or whatever, the statistics are skewed because I was clever, well clever is the wrong word really it wasn't clever, but you know I'm I'm not there in any data of going back and forth to hospital, it wouldn't have been picked up because I kept myself away from the Health Service because the Health Service are not equipped even today I don't feel they're equipped enough to deal with T1DE because they don't understand it. And so the only way we can change that is, if people put themselves forward for research. And so that's something I try and do as often as I see posters, you know I'm happy to contribute to what the change that is needed, and maybe excuse the pun, but change that, you know, change the tide a little bit, because there's a lot of people struggling and a lot of people will die younger than they need to if we don't understand it better.

Interviewer: Okay, thank you. So can you now just start with broadly just telling me a little bit about your experiences with T1DE?

Participant: yeah sure, so my diagnosis, as we mentioned just briefly before the interview, I was diagnosed at 3, and my parents took on a lot of that worry, this was back in 1990 as well and the Internet wasn't a thing, it was you know, it was incredibly scary for my parents, there's nobody else with type one in the family, I don't have any siblings, so growing up it was just me and my parents and I didn't really think it was anything... I got on you know, in school I did well, and I was academically bright in school. I was on the netball team, I played football, and again in the nineties not many girls played football, so it was a big thing, and it's great to see things are changing now. So yeah, up until secondary school, really, you know, primary I was no different to any of the kids other than I needed to take injections, I needed to have a Mars bar then, which you'd never do now it's jelly babies, or, you know, fast track glucose, but you'd have to have your hypo treatment before PE and things like that. But there was, only it didn't seem to be problematic in the way I viewed it until I was a teenager. And then all of a sudden, when you get a bit and more autonomy and you out more with your friends and and different things, I started to realise actually, I was different and I did have to work to carry this thing that none of my other friends needed to. And I think when I hit puberty I really started to notice my body changing. In hindsight that was literally because I was hitting puberty. But I think I really would have benefited from my diabetes team having a

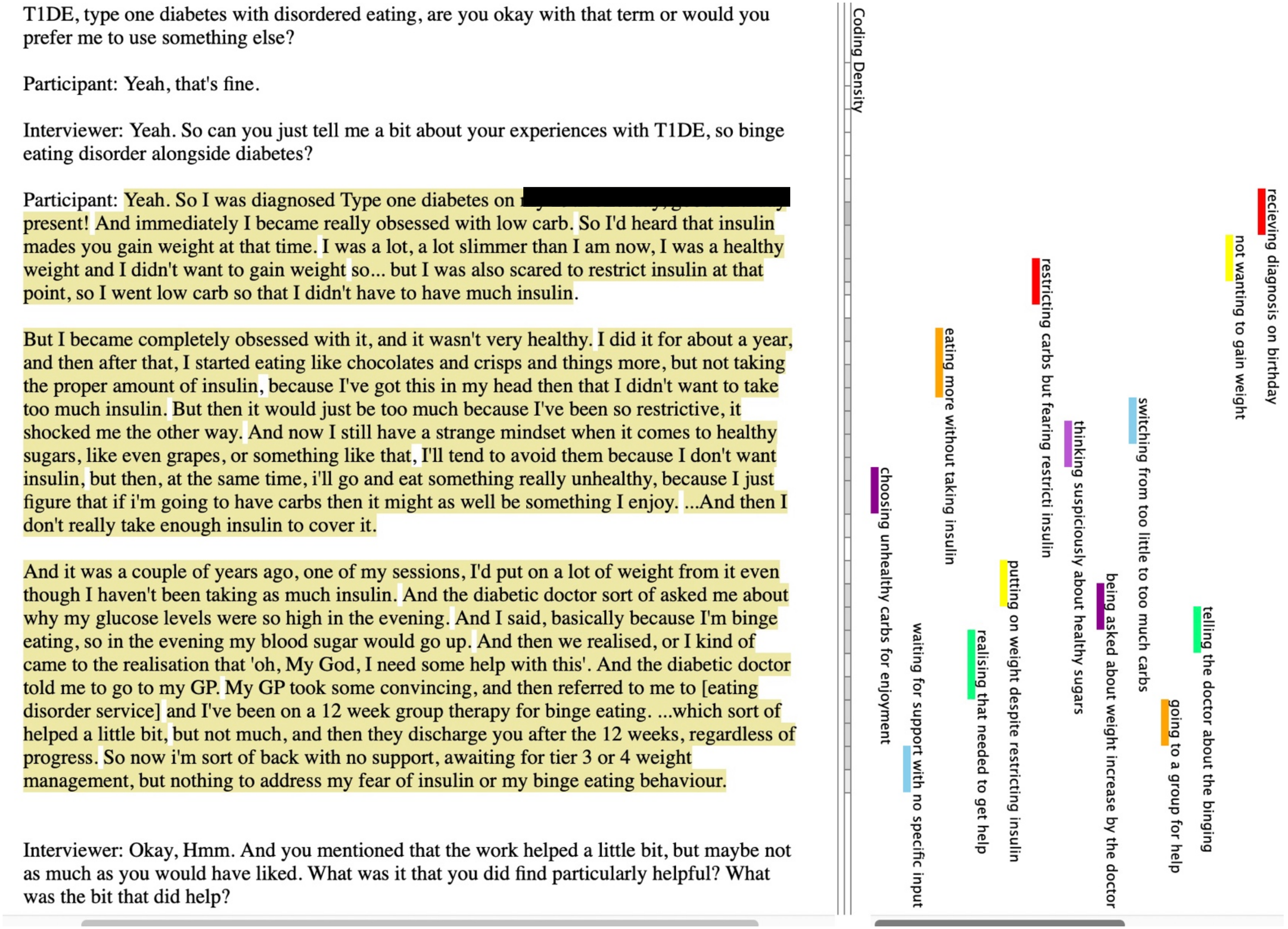
this symptom, that symptom... He said, don't, do you think you have diabetes now? And by error, well not by error, but I was in the nursing home and I was about to prick a patient, the needle was still clean, and I pricked myself by error and I thought, well, I had the suspicion and I'm suspicious now, so now I have the blood here, yeah, I'm going to test myself and I did and was quite high. So I told the doctor, yes, I think I am because yesterday I pricked my finger, and I told him the value, we use different measurement in [country] than here, it was 320 milligrams, that is about maybe 18-20 here. And yeah, you have diabetes if you have that reading, and so immediately called the hospital diabetic specialist doctor and they start me on insulin.

My parents they don't know much about it, so I think they felt guilty because they think that it's something with me like, things that people believe by by taking antibiotics too much antibiotics, or that they were guilty as well. So I remember my dad starts crying and they thought all sorts of things. I had been away for uni, and I put a lot away when I was away, weight, so they thought something I had like bad habits while I was away at uni that made that happen as well. So all that sort of things and like my family, everyone thinks it like comes from your family, like your genes. I have type 2 older people, but no, no one type one, as far as what we know, because well my grandfather's mother died quite early and no one knows why, and things like that so you don't know. But nothing that we know would indicate that would happen. I was always healthy, just normal. Sore throat and infections and things that kids have, but it was nothing different from that, I was never in hospital until being an adult. So yeah, so that was the diagnosis. And at first, when I was, it was perfect, eating perfectly and doing all the insulin on time, and HbA1C dropped quite dramatically to start with, and things like that until the weight came in the way. And first of all, I thought was not type one, because again, I believed type one would be just younger people that was something I was not expecting, not at that age.

Interviewer: And what was that like sort of mentally as well, just starting to realise that you have type one diabetes?

Participant: I is a bit of a numb period of my life, because as I said, it was really a rough year and [redacted] So everything was about that. And I completely put my diabetes away mentally and things away like that aside. She was the main thing, and everywhere else as well, we focus on that. That was our big problem in that year. So I think, I never gave me, myself time that time to kind of process of accepting and wondering why and fix. That was just something I had to deal with, because no one else has time to help me with that that, yeah that was a rough time.

Interviewer: That sounds like a very hard time. Can I ask you a little bit more around that



T1DE, type one diabetes with disordered eating, are you okay with that term or would you prefer me to use something else?

Participant: Yeah, that's fine.

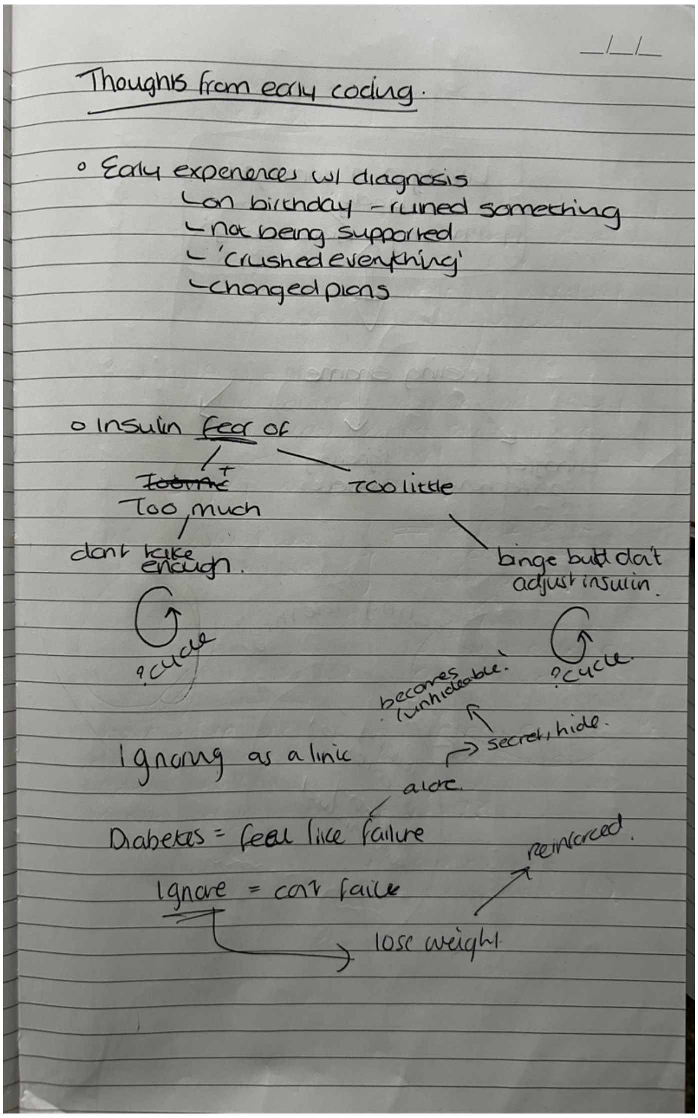
Interviewer: Yeah. So can you just tell me a bit about your experiences with T1DE, so binge eating disorder alongside diabetes?

Participant: Yeah. So I was diagnosed Type one diabetes on [redacted] present! And immediately I became really obsessed with low carb. So I'd heard that insulin mades you gain weight at that time. I was a lot, a lot slimmer than I am now, I was a healthy weight and I didn't want to gain weight so... but I was also scared to restrict insulin at that point, so I went low carb so that I didn't have to have much insulin.

But I became completely obsessed with it, and it wasn't very healthy. I did it for about a year, and then after that, I started eating like chocolates and crisps and things more, but not taking the proper amount of insulin, because I've got this in my head then that I didn't want to take too much insulin. But then it would just be too much because I've been so restrictive, it shocked me the other way. And now I still have a strange mindset when it comes to healthy sugars, like even grapes, or something like that, I'll tend to avoid them because I don't want insulin, but then, at the same time, i'll go and eat something really unhealthy, because I just figure that if i'm going to have carbs then it might as well be something I enjoy. ...And then I don't really take enough insulin to cover it.

And it was a couple of years ago, one of my sessions, I'd put on a lot of weight from it even though I haven't been taking as much insulin. And the diabetic doctor sort of asked me about why my glucose levels were so high in the evening. And I said, basically because I'm binge eating, so in the evening my blood sugar would go up. And then we realised, or I kind of came to the realisation that 'oh, My God, I need some help with this'. And the diabetic doctor told me to go to my GP. My GP took some convincing, and then referred to me to [eating disorder service] and I've been on a 12 week group therapy for binge eating. ...which sort of helped a little bit, but not much, and then they discharge you after the 12 weeks, regardless of progress. So now i'm sort of back with no support, awaiting for tier 3 or 4 weight management, but nothing to address my fear of insulin or my binge eating behaviour.

Interviewer: Okay, Hmm. And you mentioned that the work helped a little bit, but maybe not as much as you would have liked. What was it that you did find particularly helpful? What was the bit that did help?



__/__/__

Thoughts from early coding.

- Early experiences w/ diagnosis
  - on birthday - ruined something
  - not being supported
  - 'crushed everything'
  - changed plans

- Insulin fear of

~~Too little~~ Too much

don't take enough.

?cycle

Too little

binge but don't adjust insulin.

?cycle.

Ignoring as a link

Diabetes = feel like failure

alone.

secret, hide.

becomes unhideable.

Ignore = can't fail

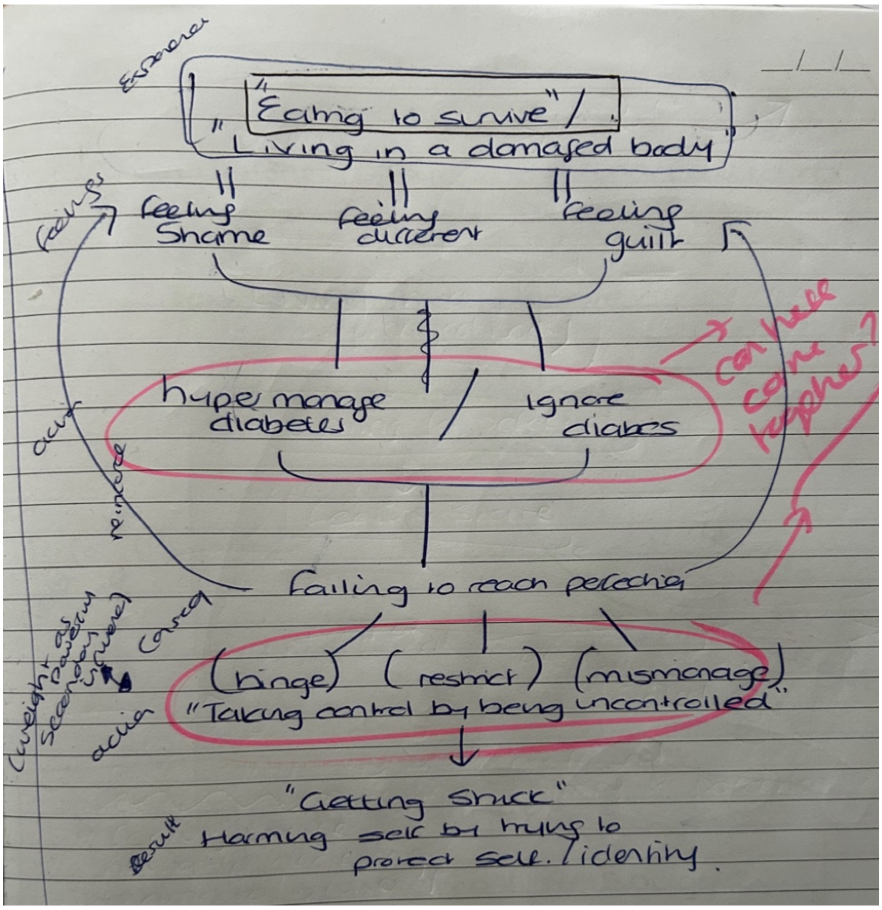
lose weight.

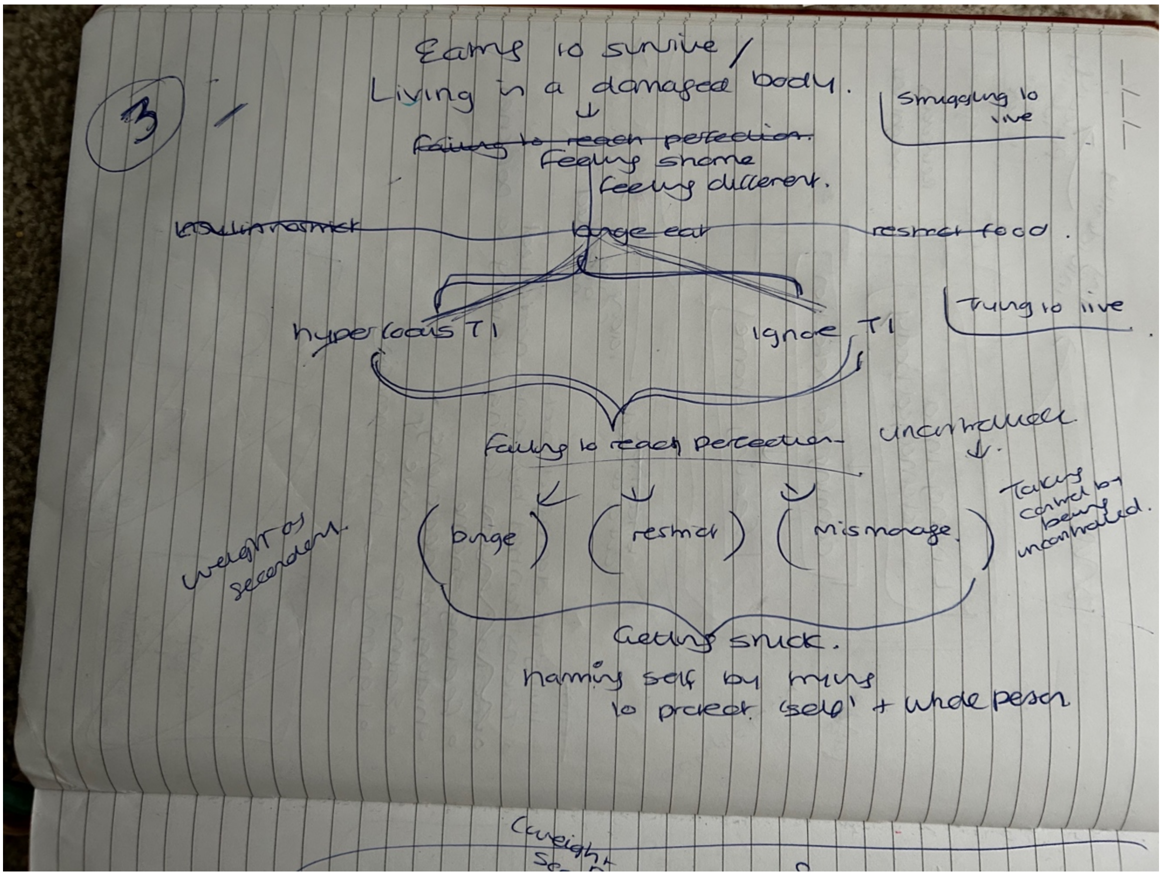
reinforced.

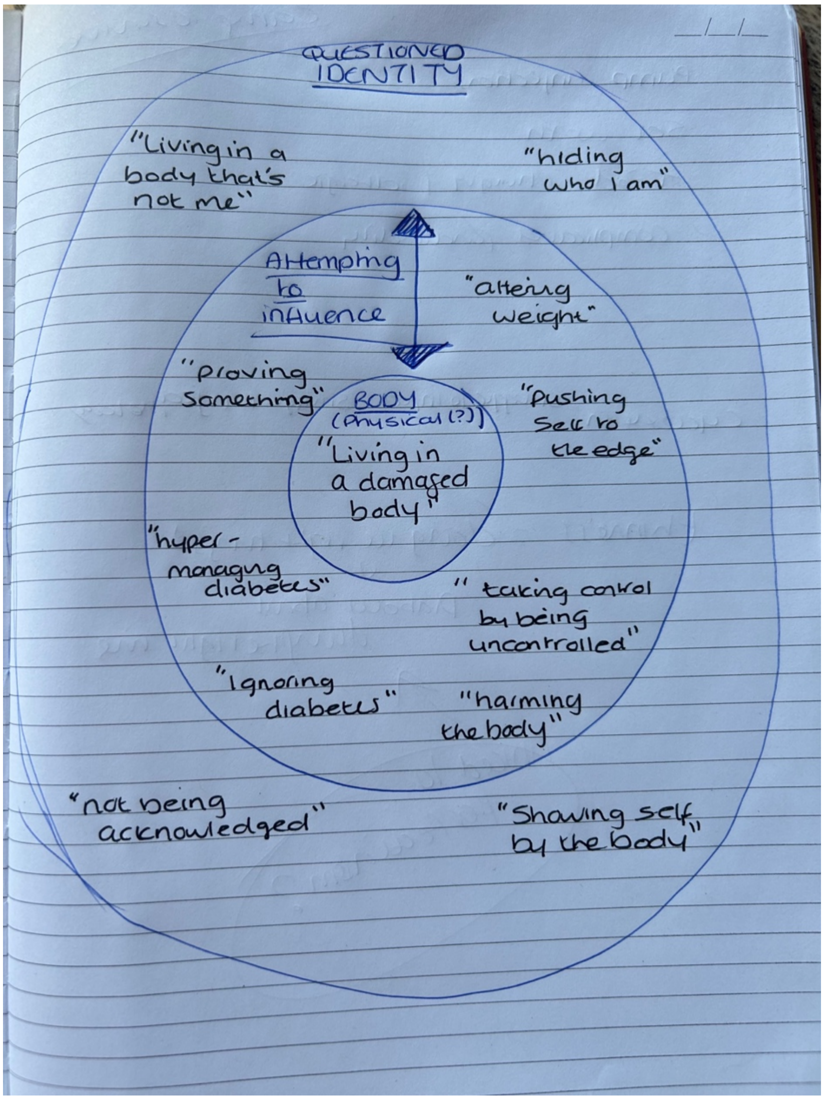

Worrying about being judged
Acknowledging the problem
Being uncomfortable with self
Feeling proud in pregnancy
Valuing physique
Believing something that isn't rational
Never being used to diabetes
Not accepting diabetes
Mentally struggling w/ diabetes
Bathing in misery of T1D
Being ashamed of body
Feeling unhappy in body
Asso weight w/ failure
Feeling disheartened
Being obsessed w/ carbs
Eating to survive
Always having to do better
Aiming for perfection
Pushing self to the edge
Reaching a low point
Spiralling with guilt
Diabetes being theoretically easy
Feeling guilty re T1DE
Not knowing what to do
Being stressed by T1D management
Feeling insulin in the body
Being a 'bad diabetic'
Always
Being judged
Feeling like a failure
Always having to do better
Escaping control
Physically experiencing diabetes
Eating to survive
Living in a damaged body
Being alone
Coping with mismanagement
Using misconceptions as a coping strategy
Wanting to be small and unnoticeable
Being driven to restrict insulin by MH
Losing weight as a nice secondary gain
Treating diabetes + MH/ED separately
MH being expressed in blood sugar
Having to return to healthcare
Internalising the shame
Not trusting own perception of self
Needing to be rescued
Not caring about self
Living in a damaged body

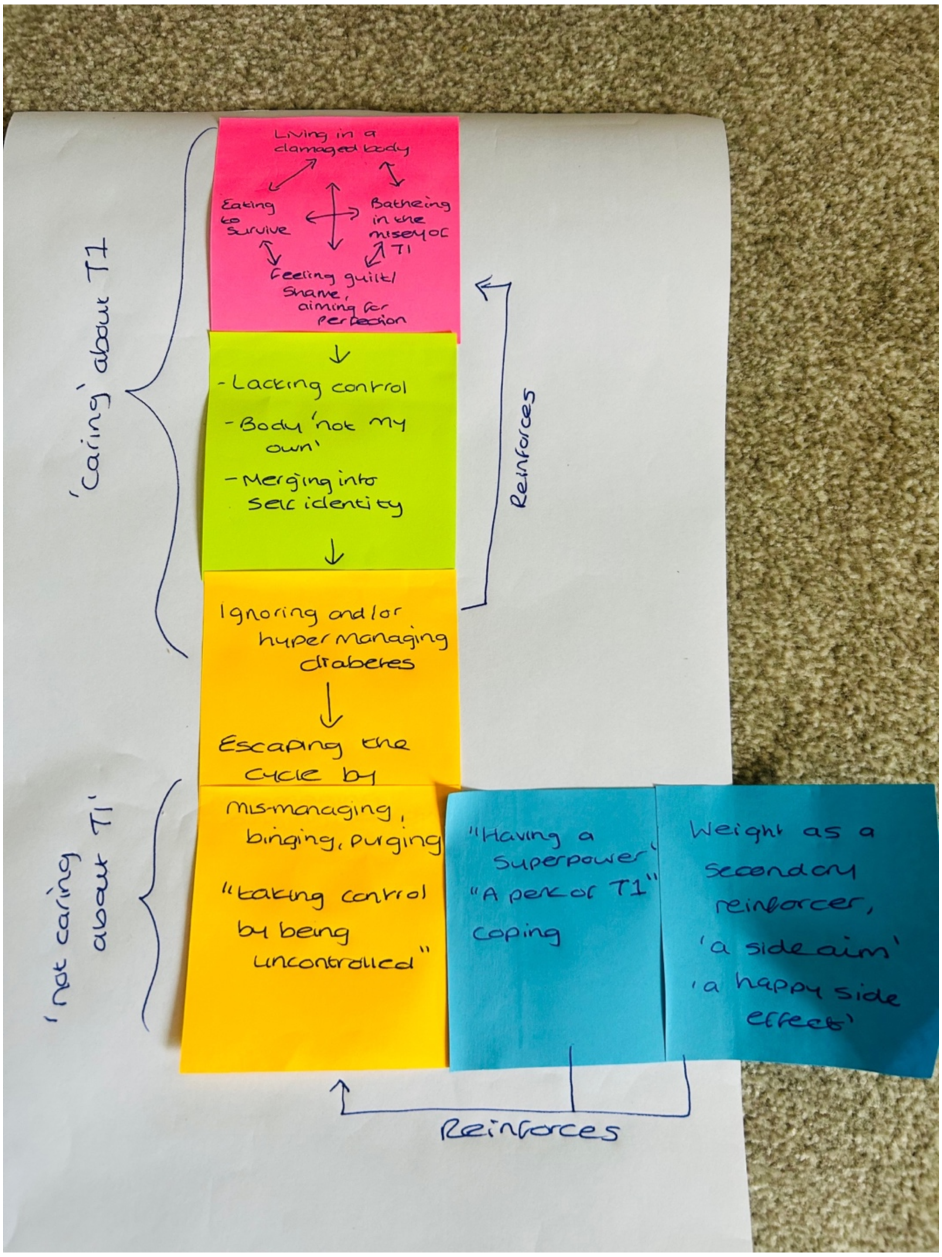

Believing something that isn't rational
Worrying about being judged
Acknowledging the problem
Being uncomfortable with self
Feeling
Never being used to diabetes
Asso weight w/ failure
Diabetes as
Bathing in misery of T1D
Being ashamed of body
mentally struggling w/ diabetes
Feeling unhappy in body
Being obsessed w/ carbs
Feeling disheartened
Marked by comments re weight
Pulling out of spirals
Valuing physique
Influencing the body to lose weight
Aiming for perfection
Always having to do better
Controlling by being uncontrolled
Escaping control
Never letting go of control
Pushing self to the edge
Reaching a low point
Eating to survive
Stress mimicking hypo
needing to eat
Comforting by eating
Binging on insulin
Getting a release by vomiting
Never truly out of T1DE
Hiding T1DE
Mismanaging to cope
Proving self as able
Becoming T1DE advocate
Needing support that doesn't exist
Hearing myths about diabetes
Feeling misunderstood w/ T1DE
Wishing to be normal
Being different from others
Keeping away from health service
Being isolated
Feeling like T1DE is made up
Getting attention in hospital
Parents being scared
Feeling insulin in the body
Being surprised by T1D dx
losing weight binging / purging
Being unable to escape diabetes
Gaining weight with insulin
Being a 'bad diabetic'
Discovering about insulin restriction
Being complacent w/ injections
Being uncomfortable in clinic
Disengaging with Diabetes
Needing contact w/ people doing well
Managing diabetes ok when young
Diabetes being theoretically easy
Always
Fighting for T1 diagnosis
Having other life stress when diagnosed
Hyper-focusing on diabetes
Ignoring diabetes
Living in damaged body
Straining r/ship w/ insulin
Being discharged regardless of progress
having undiagnosed T1DE
Struggling to inject

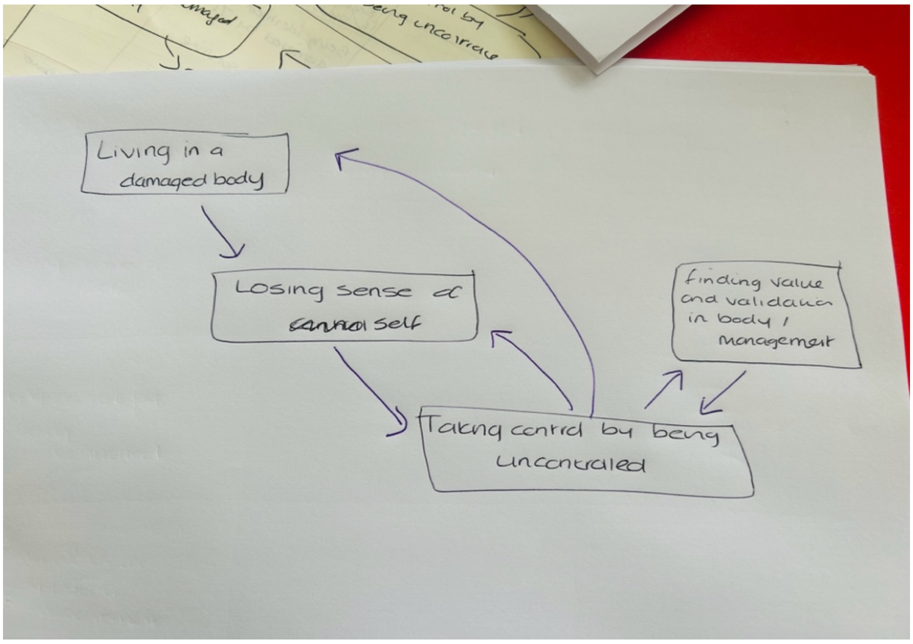
Appendix L: Analysis extracts: theory building

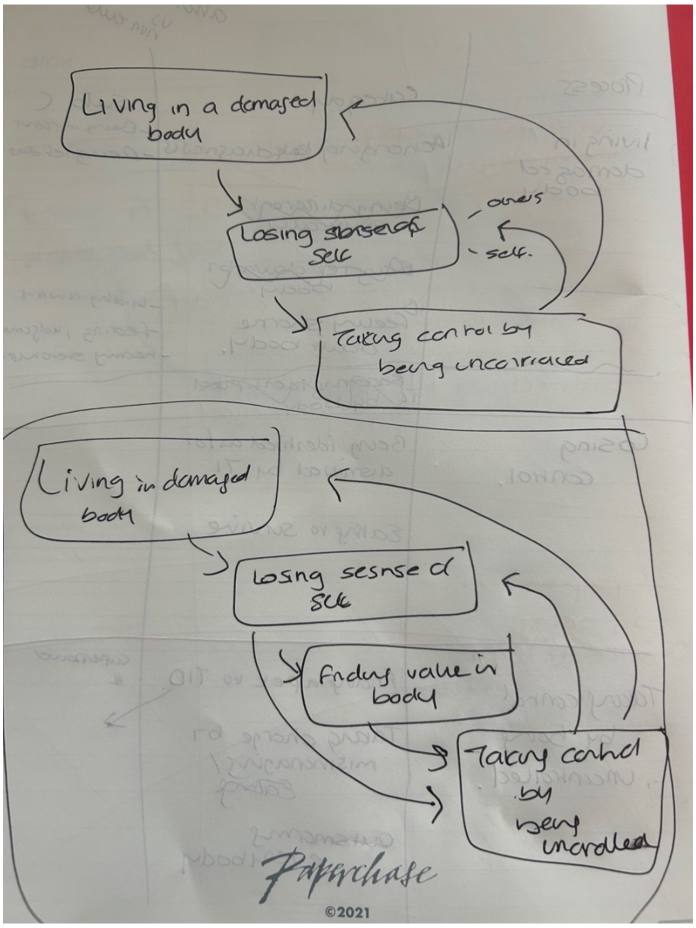


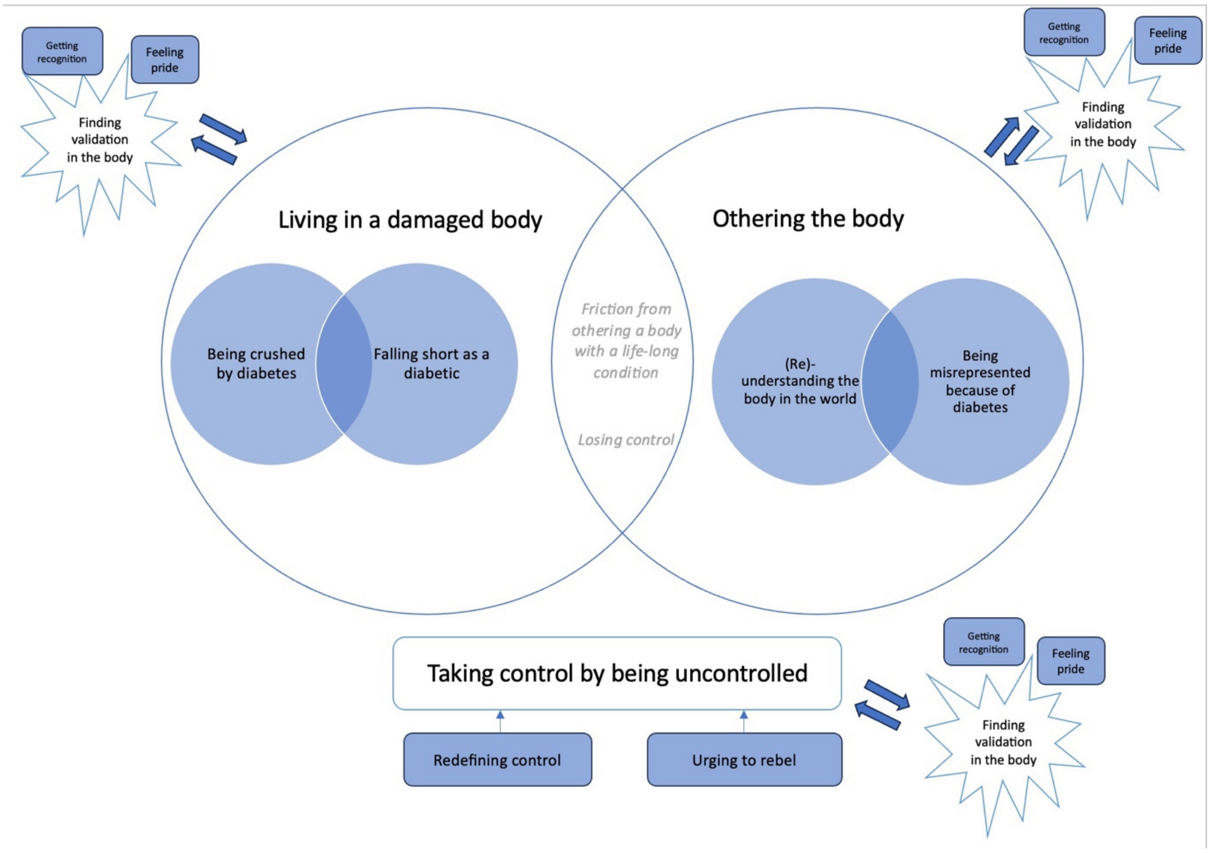



QUESTIONED IDENTITY
"Living in a body that's not me"
"hiding who I am"
Attempting to influence
"altering weight"
"proving something"
BODY (physical (?))
"pushing self to the edge"
"Living in a damaged body"
"hyper-managing diabetes"
" taking control by being uncontrolled"
"Ignoring diabetes"
"harming the body"
"not being acknowledged"
"Showing self by the body"


Living in a damaged body
Eating to survive
Batheing in the misery of T1
Feeling guilt/ shame, aiming for perfection
- Lacking control
- Body 'not my own'
- Merging into self identity
Ignoring and/or hyper managing diabetes
Escaping the cycle by
mis-managing, binging, purging
"taking control by being uncontrolled"
"Having a superpower"
"A perk of T1"
Coping
Weight as a secondary reinforcer,
'a side aim'
'a happy side effect'
'Caring' about T1
'not caring about T1'
Reinforces
Reinforces


Living in a damaged body
Losing sense of ~~control~~ self
finding value and validation in body / management
Taking control by being uncontrolled


Living in a damaged body
Losing ~~sense of~~ self
– others
– self.
Taking control by being uncontrolled
Living in damaged body
losing sesnse of self
finding value in body
Taking control by being uncontrolled


Getting recognition
Feeling pride
Finding validation in the body
Getting recognition
Feeling pride
Finding validation in the body
Living in a damaged body
Othering the body
Being crushed by diabetes
Falling short as a diabetic
Friction from othering a body with a life-long condition
Losing control
(Re)-understanding the body in the world
Being misrepresented because of diabetes
Taking control by being uncontrolled
Redefining control
Urging to rebel
Getting recognition
Feeling pride
Finding validation in the body