A study of letters written to glucose monitors by individuals living with type 1 diabetes and with experience of disordered eating.

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Foreword

To the Little White Disc

To the little white disc that sits on my arm
I know you mean well and won't do any harm
They say you're like gold dust, a miraculous 'cure-all'
A precious panacea (even though you're so small)
But you look so clinical, so cold and austere
Surely a 'cure-all' shouldn't look so severe?
You reside on my arm like a parasite, an intruder
Yet you elucidate with aplomb the caprices of my disorder
Your duplicity bewilders me: to love or to hate?
You disgust me, still, I heartily appreciate
The ease you bring to this disease I suffer
Without you I am more unlike any other
Your name is Libre and I'll admit I feel free
But the fact is nothing can liberate me
Pumps, discs, injections and all
They try their best but I am in thrall
Slave to my own body: a hostage, imprisoned
My body: the cause of my tumult and division
But I can't and I won't bring myself to attack
The very body that causes my eyes to contract
When the light is too bright to protect me from blindness
I shouldn't treat it with anything less than kindness
But when you take up residence on my arm, sitting proud
You cannot blame me for voicing aloud
How foreign, how strange your presence feels
A visual reminder: impossible to conceal
So if I can't then I won't, I won't hide you away
A myriad of questions when you're on display
"What? How? Can I touch? Does it hurt?"
Begrudgingly smiling my answer is curt
All this you bring to my table of life
Overflowing with fruit but none of it ripe
Tainted, tarnished, knowing you're there
Ubiquity, immanence, for that you've got flair
I say all of this but my need for you grows
My highs are too high and my lows are too low
When you're not on my arm, sitting pretty, sitting proud
The truth is I need you, and until I don't, you're allowed.

Sylvie Agnello

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Glossary

Term	
Type 1 Diabetes	Type 1 diabetes is an autoimmune condition where the body's immune system attacks and destroys the insulin-producing beta cells in the pancreas. As a result, the body produces little or no insulin. People with type 1 diabetes require indefinite medical treatment with insulin to manage their blood sugar levels; insulin is administered via daily insulin injections or an automated insulin pump. Type 1 diabetes often develops in children and young adults, but it can occur at any age (WHO, 2024., Diabetes UK, 2024a).
Diabulimia	The intentional restriction or omission of insulin doses by individuals with Type 1 diabetes, in order to lose weight or prevent weight gain. This can happen alongside other behaviours such as restricting food, over-exercising, binging, self-induced vomiting, and using laxatives to try to control weight. Diabulimia is not an official diagnosis and sometimes the term T1DE is preferred or is used interchangeably with diabulimia. This is because some feel that the term diabulimia does not accurately represent the condition, or the nuances of disordered eating behaviours in individuals with T1DE (Diabetes UK, 2024b)
T1DE	T1DE, or type 1 diabetes and disordered eating is sometimes used interchangeably with the term diabulimia, referring to individuals who restrict or omit insulin to lose weight or prevent weight gain weight, engage in other disordered eating behaviours such as restricting

food, over-exercising, binging, self-induced vomiting and using laxatives to try to control weight. However, in recent years some have used the term T1DE to encapsulate a slightly broader disordered eating experience. Some would now also include other forms of disordered eating, like bulimia or anorexia under the classification of T1DE (JDRF, 2024).

Flash glucose monitor

A Flash Glucose Monitor (FGM) is an electronic device used to track glucose levels. The most well-known FGM system is the FreeStyle Libre (Abbott Laboratories Ltd.). The device contains a small subdermal (insets under the skin) sensor which measures glucose levels in the interstitial fluid. The device, which is most commonly placed on the upper arm, is worn continuously by the user. With the first generation FGM's an individual had to scan their sensor with their paired device(s) to see their reading and it would not automatically alert them to low or high blood sugars. The newer versions of FGM's such as the Freestyle Libre 2, now provide real-time readings on a phone or other paired device without having to scan the sensor, and FGM's can also be set to sound an alarm if blood sugars are too low or too high (Abbott Laboratories Ltd, 2024).

Continuous glucose monitor

A Continuous Glucose Monitor (CGM) is an electronic device used to track glucose levels in real-time. It is a device containing a small sensor that is inserted just under the skin typically on the abdomen or arm which measures glucose levels in the interstitial fluid. When using a CGM, readings show up automatically on a phone or other paired device without having to scan the sensor and CGM's can

	also be set to sound an alarm if blood sugars are too low or too high (NHS, 2021).
Closed loop insulin pump	A closed-loop insulin pump, or automated insulin delivery (AID) system, is an advanced technology used in diabetes management. It combines continuous glucose monitoring (CGM) with an insulin pump to automatically adjust insulin delivery (Diabetes UK, 2024c).
Basal insulin	Also known as long-acting insulin, basal insulin refers to long-acting insulin that is administered (typically via injection) once or twice daily. This is required to maintain consistent bloods glucose levels during periods of fasting (throughout the day and overnight) (Diabetes.co.uk. 2023., NHS, 2023).
Bolus insulin	Bolus insulin is a dose of short-acting and/or rapid-acting insulin that is specifically taken at mealtimes to manage blood glucose levels spikes following intake of food (Diabetes.co.uk, 2023).
Catabolic state	Catabolic state refers to a metabolic state in which the body is breaking down muscle and adipose tissue (fat) as an energy source. In diabetic patients this can lead to a life-threatening condition called diabetic ketoacidosis (Healthline, 2018).
Diabetic ketoacidosis (DKA)	Acutely, in an insulin-deficient state, glucose transport into cells is inadequate to where cells cannot use glucose for energy, leading to cellular starvation. In response, the body enters a catabolic state (as described above), resulting in the production and thus circulation of

	ketone bodies in the blood. Diabetic ketoacidosis (DKA) ensues, resulting in life-threatening hyperglycaemia (high blood glucose), ketoacidosis (low blood pH of <7.3), as well as hydration and electrolyte abnormalities (Lizzo et al., 2023).
Glycaemic control	Glycaemic control refers to the maintenance of blood glucose levels within a desirable range to prevent both hypoglycaemia and hyperglycaemia (He et al., 2022).

Abstract

In recent years, diabetes technologies have advanced significantly, as such, flash and continuous glucose monitors (FGM/CGM) are more widely accessible. To date, little research has explored the specific benefits or pitfalls that FGM/CGM use may come with for individuals with type 1 diabetes and disordered eating (T1DE). Therefore, this study aimed to explore the relationship that those living with type 1 diabetes and experience of disordered eating have with their FGM/CGM. This qualitative study asked participants to write letters addressed to their FGM/CGM. These letters were analysed using reflexive thematic analysis (RTA) to explore individuals with T1DE relationship to the device. Four themes were constructed: 'I Don't Always Like or Want You...I NEED You... but I Wish I Didn't', 'Facing the Facts', 'You are Intertwined with Disordered Eating', 'You Communicate with Others'. Each theme comprises subthemes. The themes demonstrate how participants appeared to have a dichotomous and nuanced relationship to their FGM/CGM, identifying both positive and negative aspects of their relationship to the device. There appears to be an interplay between the FGM/CGM and disordered eating which may be specific to individuals with T1DE. Implications including recommendations for integrated diabetes and disordered eating care and development to psychological care are discussed.

1. Introduction

1.1 Overview

This study explores the relationships that individuals with type 1 diabetes and experience of disordered eating have with their flash or continuous glucose monitor (FGM/CGM), a device used to monitor blood glucose levels. This study utilised a novel data collection method - letter writing - with data analysed using RTA (Braun & Clarke, 2023). This introductory chapter will detail my personal and epistemological stance, thereafter, placing the research in the wider context of the topic area by exploring current understandings of diabetes, developments in diabetes technology, and type 1 diabetes and disordered eating (T1DE). In doing this, a gap in the literature is noted, which can be addressed by the study proposed. Following this, reflections are shared on how letters were considered as the data collection method for this study. To better understand how this novel form of data collection could be operationalised for this study, and more broadly to support researchers using the method in future, a systematic methods review exploring how letters are used within qualitative research was undertaken. The chapter concludes with the rationale for the current study and a statement of the research aims and question.

1.2 Personal and Epistemological Position

1.2.1 Positionality.

I am a white British UK born cis-gendered woman who has had access to education. I am an outsider to some of the characteristics of the participants, in that I do not have an experience of type 1 diabetes, wear diabetes technology or experience disordered eating. My learning around type 1 diabetes and disordered eating began

whilst working in a specialist inpatient unit for those with eating disorders. Here, I witnessed the challenges of managing type 1 diabetes alongside the experience of an eating disorder, and the limitations in care provided to individuals experiencing this. Working within an eating disorder setting encouraged me to reflect on the complexity of mine, and of others, relationships to food and body image. Although I do not consider myself to have experienced disordered eating, and that for most part I have had a steady relationship with food, I cannot say that I have been left completely unimpacted by wider historical, social and cultural narratives and views around eating and bodies. For example, having grown up in the 90s/2000s amongst western beauty ideals, and still experiencing the 'thin ideal' portrayed in the media, I have a wavering relationship to the way I perceive myself, and experience both satisfaction and dissatisfaction about my body. In this sense, I may share some experiences with those taking part in the research, who's experience may also be shaped by society's expectation on bodies. I acknowledge that coming to this research I had less understanding and knowledge of diabetes and diabetes management. As such, I have attempted to educate myself by engaging with those with lived experience and by reflecting on preexisting ideas I held about diabetes. For example, recognising I held stigmatising views that type 2 diabetes could be solely the result of poor lifestyle choices and had limited knowledge about the differences between type 1 and type 2 diabetes. On learning more about diabetes and from my understanding of eating disorders, my feelings about individuals with T1DE and their experiences, are those of warmth and compassion. I have a deeper understanding and respect for the great expectations placed on them and the challenges they face in an ableist society with body 'ideals'.

These factors of my identity and positionality will have contributed to how I am perceived by participants, and how I have interacted with this research. Rather than eliminating my influence, I have attempted to attend reflexively to my thoughts and potential biases throughout the project through various reflexivity practices which I have shared to aid transparency (Table 13). Alongside Table 13, some sections of the submission have been written in the first person to allow me to more easily share my perspectives which has aided reflexivity (Yardley, 2000). Although, Table 13 and sections written in the first person may more easily identify some reflexive thoughts, it is important to keep in mind that all decisions and the project will have been shaped by my identity and positionality, ranging from the literature I have accessed and engaged with, to the analysis of the data.

1.2.2 Ontological and epistemological position.

This research was conducted by drawing on a critical realist philosophical perspective. Critical realism combines a realist ontology with a relativist epistemology (Willis, 2022). From this ontological perspective, it is indicated that there is a reality that exists irrespective of our observation of it (Fletcher, 2017). This is integrated with a relativist epistemological stance which suggests that this reality is to an extent affected by our ideas about it, for example there can be numerous interpretations of the same object/thing. This suggests that the process of data acquisition can bring us closer to reality but requires interpretive understanding (McEvoy & Richards, 2003). Applying these ideas to this research, this could be understood by thinking of FGM/CGM as something that is independent of us, and the relationship to it will be subjective and filtered by individual interpretation of it, shaped by historical, political and other contextual factors. Thus, as an individual's beliefs and values are likely to influence their perception of their relationship to their

FGM/CGM, my own experiences, beliefs and values will shape the way in which I approach and interpret the research. By paying attention to subjective perspectives, it is hoped that the complexity and nuance of human experience can be captured.

1.3 Situating the research in context

1.3.1 Diabetes Mellitus.

Diabetes Mellitus (DM) is a chronic, metabolic disease characterised by elevated blood glucose (blood sugar), which in time leads to serious damage to the heart, blood vessels, eyes, kidneys and nervous system. The condition occurs when the pancreas does not produce enough insulin, the hormone that regulates blood glucose, or when the body cannot effectively use the insulin it produces (WHO, 2024). There are two main types of diabetes, type 1 and type 2. The most common being type 2 diabetes, accounting for 90% of UK adults with diabetes (Diabetes UK, 2024). Type 1 diabetes is a rarer form, accounting for only approximately 8% of people with diabetes (Diabetes UK, 2024a).

Type 2 diabetes occurs when the body does not produce enough insulin, or the body’s cells do not react to insulin properly (NHS, 2023). Those living with type 2 diabetes may initially be encouraged to manage this by making lifestyle and dietary changes. However, most people will need to take medicine to control their type 2 diabetes, usually in the form of tablets of injections (NHS, 2023).

Type 1 diabetes is an autoimmune condition where the body's immune system attacks and destroys the insulin-producing beta cells in the pancreas. As a result, the body produces little or no insulin. People with type 1 diabetes require indefinite medical treatment with insulin to manage their blood sugar levels; insulin is administered via daily insulin injections or an automated insulin pump. Type 1

diabetes often develops in children and young adults, but it can occur at any age. There is currently no cure for type 1 diabetes, meaning that it is critical that access to affordable treatment, including insulin, is available for people living with diabetes (WHO, 2024., Diabetes UK, 2024a).

1.3.2 Emotional and psychological implications of DM.

It is widely understood that all forms of diabetes have a major impact on a person's quality of life, known as ‘diabetes burden’ (Fagherrazzi, 2023). Diabetes burden includes the physical, psychological, social and economic effects of the disease, which are thought to create an elevated mental load. This elevated mental load is a cognitive and emotional strain that comes with needing to frequently monitor the condition, the burden of treatment, and the potential complications of diabetes (Fagherrazzi, 2023).

Research has indicated that diabetes-related mental load can lead to diabetes distress (Fisher et al., 2015). Diabetes distress is a specific type of emotional burden experienced by people living with diabetes (Skinner et al., 2020). Diabetes distress can include symptoms of low mood; however these feelings are centred on diabetes related difficulties, and as such are considered distinct from other sorts of distress like depression (Poole & Hackett, 2024).

Although diabetes distress is indicated to be a distinct form of distress, it is also thought to be a predisposing factor for a broad range of psychological health difficulties such as depression and eating disturbances. For example, research has highlighted that higher diabetes distress is associated with greater eating disorder concerns, such as concerns about eating, shape or weight (Powers et al., 2017). Outside of diabetes distress, there are several specific risk factors that are thought to contribute to disordered eating in the context of type 1 diabetes. For example, the

need to carefully read food labels, the focus on weight and food intake at diabetes clinic appointments, and a constant awareness of carbohydrates or calories in food in order to match insulin requirements for meals (Partridge, 2020).

Although there is a consensus within the literature that eating disorders are more prevalent in people with type 1 diabetes (Coleman & Caswell, 2020), there is currently no formal diagnosis for disordered eating in type 1 diabetes.

1.3.3 Defining type 1 diabetes and disordered eating (T1DE).

Currently, there is little consensus on how best to define this patient group (RCPSYCH, 2022). The terminology used and understanding of the disorder is evolving and has changed over the very recent years. The term ‘diabulimia’ was popularised in the media and has been utilised in clinical practice and research. This term refers to an eating disorder in a person with diabetes, usually type 1 diabetes, where the person doesn’t take the amount of insulin they need because they are worried about gaining weight or want to lose weight (JDRF, 2024). This can happen alongside other behaviours such as restricting food, over-exercising, binging, self-induced vomiting and using laxatives to try to control weight. Some people don't stop or reduce their insulin, but instead control their weight and shape through food restriction or over-exercise, which indirectly limits the amount of insulin required. Some feel that term diabulimia is insufficient to describe eating disorders in individuals with type 1 diabetes, as it can be misinterpreted, and does not capture the broad range of eating problems that may be experienced (Wisting & Snoek, 2020). As research and understanding has progressed the term type 1 diabetes and disordered eating (T1DE) has become more utilised, by researchers, clinicians and those with lived experience. Sometimes the term T1DE is used interchangeably with the term diabulimia, however, in recent years T1DE has begun to encapsulate a

slightly broader disordered eating experience. Some would now also include other forms of disordered eating, like bulimia or anorexia under the classification of T1DE (JDRF, 2024).

Although there is no consensus at present, there is currently a proposed diagnostic criterion for T1DE (RCPSYCH, 2022). This describes three criteria alongside the presence of type 1 diabetes: 1) Intense fear of gaining weight, or body image concerns, or fear of insulin promoting weight gain; 2) Recurrent inappropriate direct or indirect restriction of insulin (and/or other compensatory behaviour to prevent weight gain); 3) Presenting with a degree of insulin restriction, eating or compensatory behaviours that cause at least one of the following: harm to health, clinically significant diabetes distress, impairment on daily functioning.

A distinction has also been made between the terms disordered eating behaviours (DEB) and eating disorders (ED) (Dziewa et al., 2023). DEB being described as ‘subclinical’ eating behaviours that have an impact on an individual’s physical and psychological wellbeing. Whereas ED are considered to be a clinical diagnosis, diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2013). This involves specific criteria related to the severity, degree, and frequency of disordered eating behaviours. As such, DEB may encompass a range of problematic eating behaviours and attitudes that may not yet meet the criteria for a formal eating disorder diagnosis but have the potential to develop into an ED (Dziewa et al., 2023).

As there is not yet a formalised diagnosis for T1DE/diabulimia, based on this terminology using the phrase disordered eating may better encompass the current understanding of T1DE. However, classifying disorders in this way has the potential to minimise the experiences of those with T1DE as ‘not severe’ enough because

there is no way to be formally diagnosed, rather than the experience in if itself not having severe consequences.

Recognising these inconsistencies, and for the purposes of this study, the terms T1DE, diabulimia and disordered eating behaviours will be used interchangeably, mirroring the language used in the references drawn upon.

Type 1 diabetes and disordered eating (T1DE) is specific to type 1 diabetes, as such the following literature and current study will focus only on experiences of people with type 1 diabetes. Exploration of disordered eating in type 2 diabetes would also be important but, due to different aetiology and treatment, to attempt to combine the two would do a disservice to both conditions.

1.3.4 Theoretical models of T1DE.

Although there are no current formal diagnostic criteria for T1DE, theoretical models have been proposed to help understand T1DE from an alternative perspective. An early model proposed by Treasure et al. (2015) described a maintenance model for disordered eating in type 1 diabetes, which was based on the transdiagnostic model for eating disorders. The transdiagnostic model of eating disorders posits that the same underlying mechanisms and processes contribute to the development and maintenance of various eating disorders. Therefore, Treasure et al. (2015) adapted this model within the context of type 1 diabetes. They identified vulnerability factors such as low self-esteem and perfectionism traits, and highlighted diabetes specific mechanisms such as the increased focus on weight and eating in diabetes management, that may compound the risk of disordered eating.

As the maintenance model described by Treasure et al. (2015) was an adaptation of the transdiagnostic model of eating disorders, one limitation noted is that this may limit formulations that can be drawn (Harrison et al., 2021), as the

previously developed components may not comprehensively incorporate the experiences of those with T1DE. Additionally, this early model was primarily based on literature and clinical experiences and may not have fully accounted for the lived experience of those with T1DE. As such, Harrison et al. (2021) conducted a semi-structured interview study to produce a new cognitive behavioural model of T1DE, drawing on lived experiences. Individual cognitive behavioural therapy formulations were developed for each participant. The categories and formulations were combined to produce two new models: a development/maintenance model of T1DE and a model of recovery and resilience to T1DE; both detailing thoughts, feelings and behaviours experienced. In the development/maintenance model, factors such as difficult experiences around diabetes diagnosis and the relentless daily management are thought to sensitise individuals to eating weight and shape cues. Whereas the recovery model identified that social support, expert healthcare at initial diagnosis and eating disorder and diabetes teams working together, alongside “good enough” psychological adaptation to diabetes, integrating type 1 diabetes into one’s identity, and self-care and compassion around eating, shape and weight changes were key protective/resilience factors.

The model by Harrison et al. (2021) also elaborates on the multiple ways that insulin might be used to influence weight and shape, such as omission of basal insulin to induce a catabolic state, induced hyperglycaemia to provoke rapid weight or fluid loss, omission of bolus insulin to avoid weight gain, and the use of nutritional or carbohydrate restriction to prevent needing to give insulin to lead to weight loss.

1.3.5 Consequences of T1DE.

The consequences of T1DE can be severe and dangerous, and literature indicates that individuals who engage in insulin restriction have a reduced average life span of

45 years compared to 58 years among those who have type 1 diabetes but do not engage in insulin restriction (Goebel-Fabbri et al., 2008). Both acute and chronic consequences of T1DE have been identified.

Acutely, in an insulin-deficient state, glucose transport into cells is inadequate to where cells cannot use glucose for energy, leading to cellular starvation. In response, the body begins to breakdown adipose (fat) tissue as an alternate source of energy (catabolism), resulting in the production and thus circulation of ketone bodies in the blood. Diabetic ketoacidosis (DKA) ensues, resulting in life-threatening hyperglycaemia (high blood glucose), ketoacidosis (low blood pH of <7.3), as well as hydration and electrolyte abnormalities (Lizzo et al., 2023). DKA can cause kidney failure, heart complications, cerebral oedema, coma, or death (Goebel-Fabbri et al., 2008).

In the long term, hyperglycaemia may result in chronic diabetes complications such as retinopathy (vision loss), nephropathy (kidney damage), neuropathy (nerve damage), increase risk of cardiovascular disease, among many others (WHO, 2024; Giri et al., 2018). Individuals who engage in diabulimia report earlier onset and increased prevalence of diabetic complications, as well as reduced quality of life, compared to individuals with type 1 diabetes who do not misuse insulin (Wilson, 2012).

Alongside the physical complications of T1DE, individuals also report psychological impacts of T1DE. A recent meta-synthesis highlighted the psychological impacts on individuals who experience diabulimia (Goddard & Oxlad, 2023). Here the synthesis identified that participants felt that there was an initial sense of control and mastery with insulin manipulation, often leading to diabulimia becoming more entrenched, and resulting in a ‘constant battle’ with impulses to

restrict or omit insulin. They identified that individuals become increasingly distressed, and the experience of chronic diabetes-related complications from deliberately and frequently mismanaging blood glucose was accompanied by intense feelings of guilt, regret, and shame in later in life.

1.3.6 Support for individuals with T1DE.

With the prevalence of disordered eating in type 1 diabetes (Coleman & Caswell, 2020), the risk factors associated (Partridge, 2020), and the potentially severe consequences experience by this group (Goddard & Oxlad, 2023; Goebel-Fabbri et al., 2008; Giri et al., 2018; Lizzo et al., 2023; WHO, 2024;), it is imperative that support and treatment needs are considered for individuals with T1DE.

Psychological and medical treatment for T1DE, where provided, often occur separately with little or no coordination between services (Wild et al., 2022). Furthermore, psychological care is often unavailable within diabetes services or for those with disordered eating that doesn't meet the threshold for eating disorder services. Research is also needed to develop effective psychological therapies for individuals with T1DE (Zaremba, 2024).

Until more recently there were no integrated diabetes and mental health pathways within NHS services in the UK, leaving individuals with T1DE to be supported either by diabetes services or eating disorder (ED) services. This has previously led to poor understanding and support. Individuals with T1DE have frequently spoken negatively about interactions with healthcare professionals, stating that they do not feel understood or taken seriously by healthcare professionals (Goebel-Fabbri, 2017). As a result, many individuals disengage from support services (Goebel-Fabbri, 2017).

In 2019, NHS England launched two pilot programmes to increase understanding of the characteristics and care needs of people with T1DE (NHS England, 2024). The aim was to trial an integrated diabetes and mental health pathway for assessment, referral and treatment. Results from studies at these pilot sites indicated that it is possible to provide effective care for people with T1DE through multidisciplinary working across physical and mental health. They found that improvements in the quality of care were achieved through collaboration, knowledge exchange and mutual support between diabetes and eating disorder teams. The project, known as the ComPASSION project, established a network for knowledge exchange by producing diagnostic criteria, treatment protocols, risk assessment documents and learning materials. It was hoped that the resources would provide a foundation for the development of similar services elsewhere (Partridge et al., 2020). There is now a T1DE site in each NHS region of England and a total of eight sites (NHS England, 2024). However, a recent parliamentary inquiry identified that there is still a lack of structured and funded strategies for T1DE (Chrisp et al., 2024).

The parliamentary report also identified other barriers to effective care, such as no clinically approved pathway to prevent and treat T1DE from NICE (JDRF, 2024), no internationally recognised criteria for T1DE, and limited interdisciplinary training. Therefore, although in recent years there have been significant advances in research and understanding of T1DE, there are still areas of support which have not been fully considered and actioned.

One area that was not identified in the parliamentary inquiry and that has received little attention for those with T1DE, is the recent advancements in diabetes technology (DT), and the increasing accessibility and prescribing of flash and continuous glucose monitors across England, Scotland and Wales (Diabetes UK,

2024d). The use of these devices within the T1DE population is not well understood (Priesterroth et al., 2021).

1.3.7 Flash and continuous glucose monitors.

Flash and continuous glucose monitors (FGM/CGM) are small electronic sensors worn on the body that measure blood glucose levels, allowing people with diabetes to keep track their glucose levels in near real-time (Fagherazzi, 2023). For many years, individuals with type 1 diabetes have checked their blood glucose levels using the finger-prick method. This method requires individuals to use a lancet to prick their finger in order to obtain a small blood sample which can be applied to a single-use test strip in a blood glucose meter. This method provides a single blood glucose measurement (Diabetes UK, 2024d). Research indicated that some individuals avoid checking their glucose levels with this method for reasons such as forgetting, injection pain, time pressure, or fearing the result (Shlomowitz & Feher, 2014).

FGM/CGM now allow glucose levels to be monitored without individuals having to prick their fingers. By linking the sensor to a phone or another device, an individual can then view their blood glucose level in near real-time. Initially when using a FGM an individual would first have to scan their sensor with their paired device(s) to see their reading, and it would not automatically alert them to low or high blood sugars (Diabetes UK, 2024d). Whereas when using the new FGM's (such as the FreeStyle Libre 2) or using a CGM, readings show up automatically on a phone or paired device without having to scan the sensor, and the new FGM's and CGM's can also be set to sound an alarm if blood sugars are too low or too high. Both device types can now be paired with an insulin pump, providing real-time blood glucose data to the pump, which automatically adjusts insulin delivery accordingly (known as a hybrid closed-loop system) (Diabetes UK, 2024c).

Both FGM and CGMs have been shown to improve glycaemic control, as well as reduce incidences of hypoglycaemia in individuals with type 1 diabetes (Dover et al., 2017; Mancini et al., 2018). Additionally, adults with type 1 diabetes using FGM or CGMs reported improvements in quality of life compared to those using the finger pricking method to self-monitor blood glucose (Ish-Shalom et al., 2016; Polonsky et al., 2017). Furthermore, a recent systematic review identified that individuals feel safer while wearing a CGM, noting that it provides reassurance when doing daily activities (Messer et al., 2017). CGM users describe a sense of independence (Messer et al., 2017), and those using FGM have voiced a sense of freedom which allowed them to have more choice in their lives (Gleeson et al., 2019).

However, while diabetes technologies can offer many benefits, research has also identified some challenges experienced by users. For example, not all individuals will have access to diabetes technologies, some individuals find the devices intrusive, and the alarms are found to be frustrating (Messer et al., 2017). Other difficulties experienced by users are that the device can be uncomfortable to wear, they can cause an emotional burden to the user and those around them, and they can make diabetes visible to others, leaving the wearer feeling different from others (Messer et al., 2017). Fagherazzi (2023) also notes that they cannot solve some of the social and emotional challenges that come with living with diabetes, such as stigma and social isolation.

Additionally, Wallace et al. (2022) examined eating behaviours and relationship to food in individuals with type 1 diabetes without eating disorders whilst using the Free Style Libre FGM. This study found that FGM use influences diet, including what, when, why and how much food users eat. For example, participants

noted being more conscious of what they were eating and the effect that it had on their blood glucose levels whilst using a FGM. As the FGM has been identified to have an impact on eating behaviours in those without disordered eating, it is possible that may also be the experience of those with T1DE. Due to the increased focus on numbers (i.e., glucose levels, activity and carb portions) that the device requires, which are thought to contribute to the development of T1DE (Partridge et al., 2020), it could be anticipated that the device may act as a contributing factor to the development disordered eating behaviours. Or, if a FGM/CGM is provided to those who already experience disordered eating, we may anticipate that it could lead to further difficulties given the impact on eating behaviour and relationship with food identified by Wallace et al. (2023). However, to date research has not qualitatively explored this.

1.3.8 Considering diabetes technology and T1DE.

Only a small amount of research thus far has looked at the use FGM/CGM in individuals with type 1 diabetes and disordered eating, primarily focusing on CGM data and self-reported quantitative measures (Priesterroth et al., 2021). For instance, Rama Chandran et al. (2018) analysed and compared CGM data for individuals with type 1 diabetes and individuals with T1DE; results indicated that individuals with T1DE spent four times longer in level 2 hyperglycaemia (a more severe form of glucose level) than individuals with type 1 diabetes not identifying as having disordered eating. A further study explored the time of day when individuals with T1DE most commonly restrict insulin; findings indicated that the frequency of insulin restriction varied by time of day; restriction was least likely in the morning, but more likely for meals and snacks eaten during the afternoon. This study did not research the reasonings for this but discussed that it may be due to possible factors such as

calorie restriction that leads to overeating later in the day, or that individuals may have less structure for later meals. The authors indicated that further research is needed to examine these factors but suggested that late afternoon is a potential important time for additional therapeutic support (Merwin et al., 2018).

In addition to exploring how the time of day may impact insulin restriction Merwin et al. (2015) aimed to identify other real-time precursors and correlates to insulin restriction and investigated the effect of administering insulin on post meal affect in individuals with T1DE. Across three days, CGM data was recorded, and participants completed quantitative surveys through automated or participant-initiated telephone calls. Merwin et al. (2015) found that negative affect and diabetes specific negative affect was a significant predictor of insulin restriction. Furthermore, increases in anxiety and guilt further increased the likelihood of restricting insulin for an upcoming meal, and insulin restriction was also more likely when a dietary rule had been broken. Additionally, findings showed that individuals who tended to restrict insulin reported higher levels post-meal affect of guilt/disgust, feeling upset about diabetes/diabetes management, or wanting diabetes out of mind. It is important to note however, that data relied on self-reported data collected over a limited period of time, restricting the conclusions that can be drawn. Furthermore, the negative affect reported was chosen from a list of emotions, limiting the emotional responses or contextual factors participants could share. Research has yet to qualitatively explore the use of FGM/CGM, which may help understand these findings with more depth.

Although there is limited published research into FGM/CGM use in individuals with T1DE, The Royal College of Psychiatrists (2022) have provided guidance on FGM/CGM use in T1DE. The guidance, which has been developed from valuable practice-based learnings, suggests that glucose monitors can be helpful in the

treatment of T1DE. For example, the guide indicates that data from the sensor could be uploaded and shared with healthcare professionals, allowing for remote specialist advice to be given; it is suggested this can be particularly beneficial for multidisciplinary working. They also note that patients may benefit from the automatic low blood glucose alarm function, which may offer them reassurance as hypoglycaemic episodes can be detected early and treated promptly. Furthermore, they suggest a reduced need for finger-pricking may also reduce diabetes-related distress. However, they also note that the decision as to whether CGM's are supportive of recovery must be taken on a case-by-case basis. The reasoning noted for this is that some patients are concerned or distressed by high blood glucose levels seen on their device, believing high blood glucose levels cause weight gain. Additionally, in a recent study exploring the role of experiences of the body and embodiment in T1DE, the researcher noted that technology was discussed by most participants in the study in some capacity (McMahon, 2023). McMahon (2023) did not aim to explore the role of technological developments; however, participants spoke of the use of technology such a glucose monitors and insulin pumps as reducing the burden of diabetes management, and that the technology was able to alleviate the pressure and stress associated with diabetes management. This suggests that blood glucose monitoring may have a significant role in T1DE management (McMahon, 2023).

1.4 Gaps in the literature and rationale for research topic

Given the findings around the eating behaviour impacts of FGM/CGMs in individuals without eating disorders (Wallace et al., 2023) and the possible positive experiences described by those with T1DE (McMahon, 2023), a need to further understand the

use of FGM//CGM in those with T1DE has been identified. Outside of quantitative research, anecdotal reports, and practice-based learning, little is known about the specific benefits or pitfalls that FGM/CGM use may come with in the T1DE population. Therefore, exploring this relationship could provide insight into the experiences of using glucose monitors for those with T1DE.

1.5 Rationale for systematic literature review

As limited research has explored the use of glucose monitors by individuals with T1DE, it was important to carefully consider how research may be conducted in a way that best supports the community to engage, whilst also considering ethical issues such as benefits and risks to participants. Furthermore, given that this population have reported not feeling understood by healthcare professionals (Goebel-Fabbri, 2008), we wanted to ensure the method of data collection used was one that could best capture and represent the experiences, thoughts and feelings of this under-researched group. In considering how best to collect data for this project, inspiration was taken from a letter written by Renza Scibilia, a blogger and diabetes activist, living with type 1 diabetes to their Doctor (Figure 1).

Figure 1

Dear Doctor letter written by Renza Scibilia

Dear Doctor

Hi. You and I are on the same side. My side. We are both championing for me to be the best I can be with the cards I've been dealt.

I thought that we would start out by me telling you what I need from you and I would love it if you did the same.

This is a relationship that works two ways. You need things from me and I need things from you. Let's get all that out on the table from the beginning.

Mutual respect is really important. I come with mine ready to give to you. I won't, however, be quite so generous if you don't demonstrate the same thing.

Judgement is not welcome in our consultations. That message is actually for me as much as it is for you, because I am totally judging you. I expect you to be judgmental and not understand me or my condition. Show me that I'm wrong. And then don't judge me for being such a pain in the arse!

My health condition is one that you know a great deal about. That is why I am coming to see you. I want to know everything you know that is relevant. But I need you to remember that I have a unique expertise in the field of Renza's Diabetes. I am the world expert in this field and I will impart everything I have learnt and continue to learn about it to you. If you could then help me make sense of that, I'd really, really appreciate it.

I am not stupid. I have a really good understanding of the health system of which I am, unfortunately, a user. I also know a lot about the technical sides of my condition. I totally get that you need to make sure that I am clear about what you are saying, but please don't dumb it down too much for me. I promise that I don't care about looking stupid. I'll ask if I don't understand.

I use humour a lot to try to deal with what is, at times, a really scary thing to live with. Sometimes you may think that my humour is not particularly appropriate. A lot of the time you won't find me funny (but for both of our sake, please pretend; I promise to ignore your fake laugh). I don't make fun of the situation because I am making light of it. Or because I don't care. I always care a great deal. But sometimes, it's what I need to get me through. I'm really not good at asking for help. But I am coming to see you because I need it. I may seem to be going the long way around getting to actually ask for what I need. Feel free to ask and prompt and even push a little.

I'll say it again. I care a great deal about my health. I want to be healthy and well and on top of everything. There will be times – and they may be extended times – where it seems that I don't care.

The important word there is 'seems'. I do care. Really. Sometimes though, it is just overwhelming and exhausting. But I really, really do care.

I have a beautiful family and a great job and a shoe collection that may make you jealous and I really like to drink coffee. I bake a lot and love old black and white films. I have wonderful friends I spend time with – frequently over a meal somewhere. Exercise and I are not mates. I read voraciously and should probably seek some sort of therapy for my inability to stop buying books. I have a thing for bright red lipstick and have too many handbags. I love Nutella. And bacon. And doughnuts. You may wonder why I am telling you this. It's because all of these things are part of my life. Just like diabetes. And it goes to explain why diabetes is not the most important thing in my life or the thing that I focus on all the time.

I'm terrified about my future. I am scared about diabetes complications, I lie awake at night worrying about the chance of my daughter getting diabetes and I fear becoming a burden on my loved ones. Diabetes is scary. It is not just a condition of numbers and lab results. It is (an unwelcome) part of my present and my future.

I solemnly swear that I will never, ever walk into your office asking you about some ridiculous cure I read about on the internet. Remember that bit about me not being stupid? But equally, the internet is where I get a lot of my support and information about living with diabetes. I have a support network of people living with diabetes from all around the globe. They build me up, tell me about new things, help me work through tough times. They are, to me, as important a part of my diabetes management as you are. Don't treat them with suspicion.

So, did you know that cinnamon can cure diabetes? I'm disconnecting my pump and eating cinnamon doughnuts and nothing more for a week to see how it goes. Just kidding. (Pretend laugh. Now.)

And finally. I want you to remember all the time that I am doing the best I can at that very moment. It may not be as much as you would like, but this isn't about you. It's probably not as much as I would like either. Acknowledging what I am doing makes me feel really great. And frequently then makes me want to do better.

Thanks for reading. I really do hope this is the beginning of a beautiful doctor and person with diabetes friendship.

Best Renza

My supervisors and I found this letter particularly powerful and moving, leading to conversations around creative research methodologies and the possibility of using letter writing as a method of data collection. Letter writing is utilised in MANTRA (Maudsley Model of Anorexia Nervosa Treatment for Adults), a specialist integrative therapy that has been developed specifically for the treatment of anorexia nervosa, in which participants write letters as part of their treatment. Here, letter writing is used as clients indicate finding it easier to write about issues rather than talk about them. It is also believed that letter writing in this population is thought to lead to stress reduction and improved mood (Schmidt et al., 2023). As some similarities are noted between T1DE and other eating disorders, such as an increased focus on weight and shape and perfectionism, (Goebel-Fabbri, 2017) it was felt that letter writing as a data collection method may be acceptable and useful to the population of individuals in this study.

The possibility of using this methodology was also discussed with the experts with lived experience of T1DE who consulted on this project. Feedback was given that letter writing would indeed be a helpful way to determine how individuals ‘actually feel’ about their glucose monitor, and that writing may allow them to discover how they feel and relate to the device. As such, we considered the idea of letter writing as the data collection method.

From a scoping search, we found that Stamper (2020) had developed some guidelines around using letter methodology, and a small amount of research papers utilising letters were identified. Stamper (2020) suggests that using letter writing as opposed to in-person interviews allowed a greater degree of confidentiality and aided in eliminating geographical barriers, thus allowing anyone to take part. Stamper (2020) also notes that other valuable qualities to letter writing are time, reflection and

distance, as these factors are thought to elicit emotional and self-reflective participant responses. Furthermore, Milligan (2005) suggests that a further benefit of data collection via letters is that participants feel more in control of the process as they are writing in the absence of the researcher.

However, outside of these reflections the scoping search identified little research utilising letters as data, and we were not able to sufficiently identify whether this methodology would be appropriate for this project and how to operationalise this methodology. Therefore, it was deemed important to conduct a methodological systematic literature review of the method of using letters in qualitative research; thereafter, an appropriate methodology could be determined and used to conduct our proposed research.

2. Systematic Literature Review

2.1 Overview

This chapter begins with an outline of the aims, scope, and process of the systematic literature review. This includes the search strategy utilised, the databases used and an overview of the inclusion and exclusion criteria. This will be followed by sharing the results of the search displayed in a PRISMA chart, and a summary of the identified papers. The data extraction method is detailed, followed by the narrative synthesis of findings.

The findings are presented in a format to allow future researchers to use as a 'how to' guide for using letters in qualitative research. As assessment of the quality of the studies was partially invited with some of the questions in the data extraction tool, some informal quality analysis has been weaved through the synthesis. As this review was synthesising methodological approaches rather than empirical evidence, and as such papers would not be excluded due to the quality of the evidence produced, the full quality appraisal comes after the synthesis to enhance the overall understanding of the methodological strengths and weaknesses of the studies included.

Following this, the summary brings together the synthesised findings of the data extraction and quality appraisal. Finally, the rationale for the current empirical study is shared, which has been developed on the wider breadth of literature included in the previous chapter, joined with the conclusions from this systematic methods review.

This systematic review aimed to answer the following question:

"How are letters used in qualitative research?"

2.2 Aims and Scope

Systematic reviews aim to find all relevant work that address a research question and produce a synthesis of the findings (Siddaway et al., 2019). In doing so, systematic reviews can draw on cumulative evidence to form more robust and broad conclusions, or help identify gaps and contraindications within the evidence base. Most commonly systematic reviews focus on the outcomes and synthesising empirical research findings from multiple studies. However, a systematic method review focuses on analysing methodologies to increase clarity and enhance collective understanding of specific methods topics that may be characterized by ambiguity, inconsistency, or a lack of comprehensiveness (Gentles, 2016). Such reviews are warranted because researchers typically lack the time to systematically search, retrieve, review, and compare the available literature to develop a thorough and critical sense of the varied methodological approaches (Gentles, 2016).

This review will be the latter: a systematic methods review. The aim of the review is to locate work that has used letters as the form of data to build a better understanding of the practicalities of using letters in qualitative research to support the current study, and future researchers in using this method. While the number of studies using letters as data is increasing, currently there is a lack of synthesised evidence about the usage, benefits, or challenges of using letters in qualitative research.

This systematic methodological review aimed to explore the following questions:

1. How has using letters as a data been operationalised in qualitative research?
2. What are the reported benefits of using letters as a data in qualitative research?
3. What are the reported challenges of using letters as a data in qualitative

research?

4. What are the recommendations for using letters as data in qualitative research?

As this is a methods review, the empirical findings from studies will not be detailed or synthesised. Instead, a narrative synthesis of methodological information and processes detailed in papers will be combined. This information will be integrated and critiqued to advance future researchers understanding of this method.

2.3 Search Strategy

To help develop search terms it is recommended to split the topic into individual concepts and consider alternative terminology for the terms (Siddaway et al., 2019). As such, the following process was conducted:

Figure 2

Search strategy

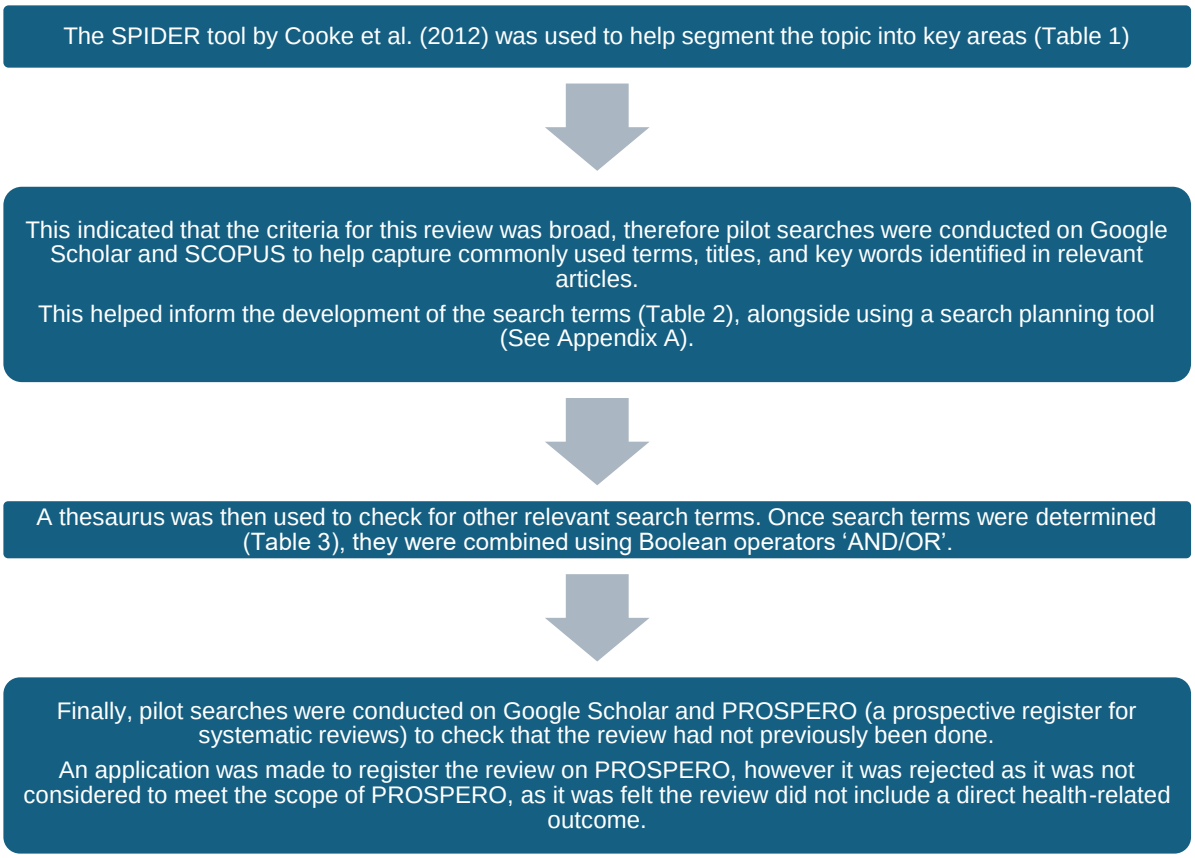


Table 2

Spider Tool

Spider Criteria	
Sample	No restrictions on sample
Phenomenon of interest	How are letters/letter writing used in qualitative research
Design	Any design that includes letter writing/letters as a data set which is then qualitatively analysed will be included. This can be handwritten, electronically written, audio recorded, web-based or app-based.
Evaluation	As this is not an intervention review and there will be no consideration of study outcomes.
Research Type	Qualitative, multi method or mixed method studies.

Table 3

Search Terms

Concept 1		**Concept 2**
	AND	
Method		“Letter writing”
OR		**OR**
“Data collection method”		“Letter-writing”
OR		**OR**
Methodology		Letter
OR		**OR**
Qualitative		“Letters”
		OR
		“Narrative”
		OR
		“Correspondence”

Cals & Kotz (2013) state that it is essential that journal titles include key search terms, and that descriptive titles inclusive of methodological design are often preferred by journals. As such, it was felt that filtering the search to ‘Titles’ only would help identify papers in which the methodological use of letters was described in detail. Two searches were undertaken on SCOPUS, first using the filter of ‘Article title’ retrieving 1652 papers, and then using ‘Title, abstract and keywords’ which retrieved 165,066 papers. The first 10% of each of the searches were compared. These preliminary searches confirmed that more relevant papers were retrieved if the search was limited to ‘Titles’ and as such this approach was adopted.

Final searches were conducted on 27th October 2023 using the following databases accessed via the University of Hertfordshire online library: Scopus, CINAHL Plus and JSTOR. The combination of these three databases was chosen to retrieve the most relevant results. As a specific condition or population was not the focus, SCOPUS and JSTOR were included for their breadth, as these databases include literature across a wide variety of disciplines (Elsevier, 2024; JSTOR, 2024). CINAHL was chosen to supplement the other databases as it a reputable and large source for allied health peer reviewed journals (CINAHL, 2024); disciplines in which qualitative research is commonly carried out. It was thought that this database may therefore add some unique references that may help inform the review. An example of an electronic database search can be found in Appendix B.

A search was also conducted using the Google Scholar advanced search tool. Using the same search terms (Table 2) and ‘Title’ filter, 5730 results were produced, and 10% of the results were reviewed. This identified no additional papers to the databases search, so no further papers in the Google Scholar search were screened.

Inter-library loan requests were made for papers found in the databases that were not available via the University of Hertfordshire library. This enabled the full texts for all papers to be accessed and assessed for this review.

2.3.1 Inclusion and exclusion criteria.

Table 4 provides a summary of the inclusion and exclusion criteria applied to the results of the searches. The types of studies included in the review were qualitative, mixed, or multi-method studies. For the purposes of this review, qualitative studies were defined as research that utilised qualitative analysis with some level of researcher interpretation (Ngulube, 2015). There is little consensus about the definition of mixed and multi-method studies (Fàbregues et al., 2021). For the purposes of this review mixed methods are defined as studies with a quantitative and qualitative element (Creswell & Clark, 2023), and multi-methods as studies with more than one method of data collection (e.g. two types of qualitative data collection methods) (Creswell, 2015).

Due to time and resource limitations, only English language papers were included. Papers where letters were not the main part of data collection, and those where analysis reduced the letter content to quantitative data, rather than used rich qualitative data with researcher interpretation, were also excluded.

Table 4

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Letters as data set	Letters are not a main part of data collection or analysis
Letters that are written for the study or pre-existing letters	No qualitative analysis is performed

Qualitative or mixed method studies where letters are qualitatively analysed	Letter writing/letters are used only as an intervention rather than research method
English Language	Case series, commentary, editorial and other opinion papers, books or book chapters, narrative/systematic reviews, conference abstract, dissertations, theses and other grey literature
Peer reviewed journal articles	

After searches were conducted, article titles were exported to Word documents, and duplicates were removed. All titles were screened; if inclusion or exclusion was unclear from the title, the abstract was reviewed before a paper was excluded. A second reviewer, who was a peer from the DClinPsy cohort at the University of Hertfordshire, then screened 10% of the search results to ensure reliability and accuracy in deciding inclusion and exclusion of papers. Reviewers were initially blinded to the other's decision, and disagreements were resolved through discussion and evaluation of inclusion/exclusion criteria. The remaining papers were then screened by reading the full article against the inclusion criteria. The second reviewer also screened the full text for all the final included papers. The citations and references of included articles were examined to identify other articles for review. All decisions were recorded in Microsoft Word.

2.4 Data extraction

Data extraction was undertaken using a template designed for the review to ensure consistent data extraction (Table 5). This checklist was adapted from a similar template utilised in a methods review looking at the use of qualitative diary methods in mental health research (McCombie et al., 2024). Due to this review having similar

aims to the current review, it was felt to be a relevant and comprehensive checklist.

Data was recorded in Microsoft Word.

Table 5

Data extraction checklist and supporting questions

Item	Guide Question
Citation	What is the citation to be used in the thesis?
Aims	What were the overall research aims?
Methodology	What methodology did the study employ? Qualitative or mixed or multi methods?
Condition/ experience/area being studied	What was the condition/experience/area studied?
Rationale for letters	Was a rationale given for using letters? What was it?
Recruitment/source of letters	Where/how were letters sourced?
Format of letters	Were letters handwritten, typed, audio recorded etc? What was the rationale for this?
Number of letters per participant	How many letters did participants write? Did they write one or more letters?
Researcher communication	Is there letter correspondence between the participants and researcher?
Total number of letters in study	How many letters were collected/and or analysed? What was the rationale for the number?
Timespan of letter completion	How long were participants given to complete letters? What was the rationale?
Nature of prompts/instructions	What were the prompts/instructions used? What was the rationale?
Who/what is the letter addressed to	Who/what is the letter addressed to? What was the rationale?

Length of letters	How long were the letters? Was a word length set by researchers? What was the rationale for this?
Qualitative analysis used	What analysis used to analyse letter data? What was the rationale for this?
Epistemological stance	Is an epistemological stance shared? If so what is it and what was the rationale?
Researcher reflexivity	Does the researcher reflect on use of self/researcher involvement?
Perceived benefits of using letters as data	Does the researcher describe any benefits of using letters as data collection? If so, what?
Perceived challenges of using letters as data	Does the researcher describe any challenge of using letters as data collection? If so, what?
Recommendations or suggestions for future research using letters	Are any recommendations or suggestions made for future researchers using letters? If so, what are they?

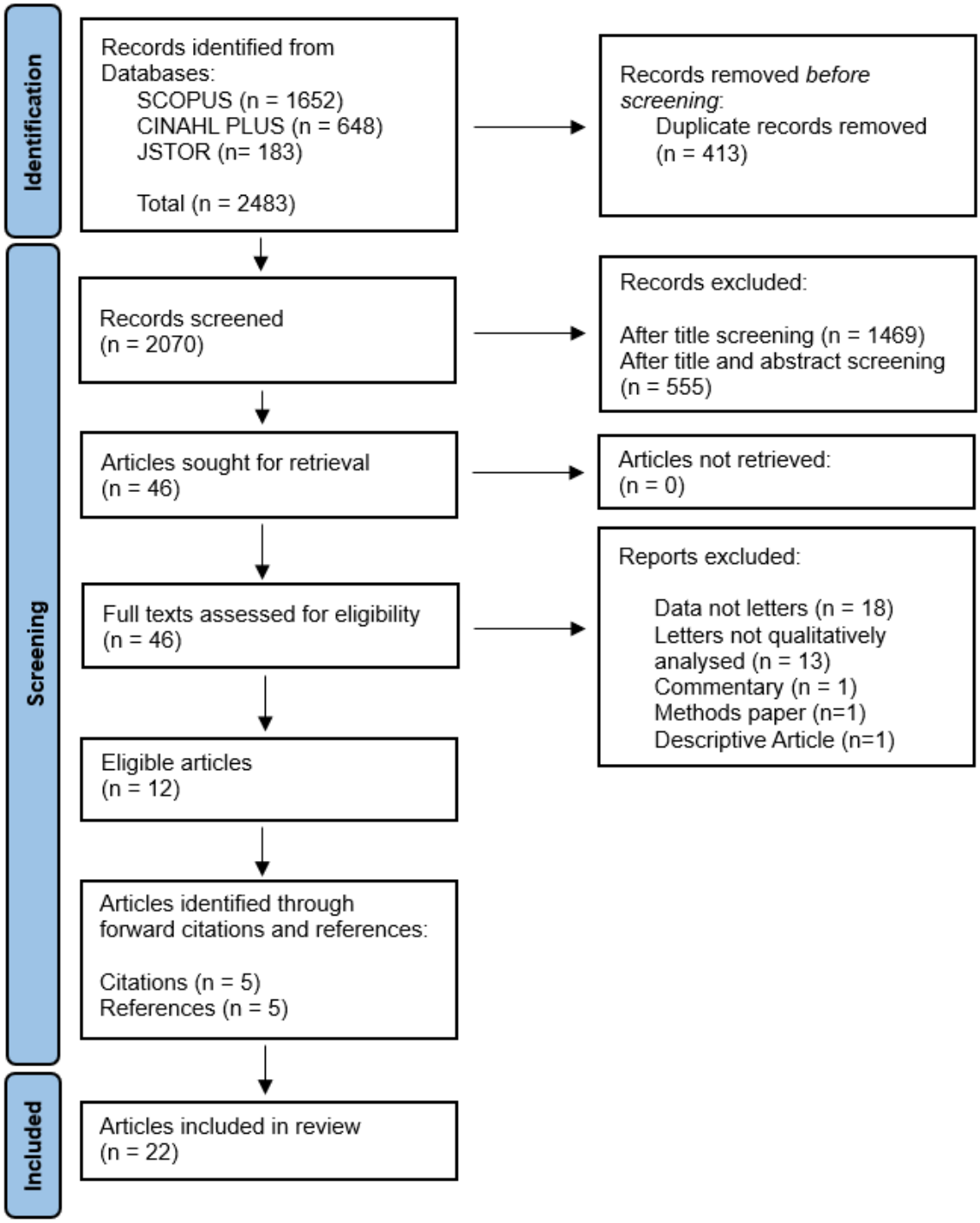
2.5 Results of the search

The search results using the above criteria and databases are detailed in the Prisma flow diagram in Figure 2. The searches produced a total of 2483 papers, of which 413 duplicates were removed. Screening titles removed 1469, and a further 55 papers were removed after abstract screening. The remaining 46 papers were reviewed in full text. Of these 46 papers, 34 were excluded for the following reasons: the data set were not letters, letters were not qualitatively analysed, or the paper was a commentary, methods paper or descriptive article. The remaining 12 papers met criteria for inclusion in the review. The reference lists and forward citations generated by Google Scholar for the 12 included papers were hand-searched for articles that also met the inclusion criteria. An additional 5 papers were found through references,

and 5 through citations (total of 10 papers). Therefore, a total of 22 papers were included in the current review.

Figure 3

Prisma Flow Diagram



The table on the following pages is a summary of the papers identified by the search (Table 6), inclusive of the results of the data extraction. For the full details see the extended table in the appendix (See Appendix C)

Table 6

Summary of papers in the systematic literature review

Paper no.	Authors and title	Condition/ or experience being studied	Method	Analysis	Recruitment/source of letters	Number of letters
1	Cummings, C. & Gruenert, S. (2011). **The fan letters of Ryan White: a method to promoting prevention**.	The fan letters of Ryan White, a child who died from complications related to AIDS.	Qualitative Letters	No details provided	Existing fan letters	**Per participant:** N/A **In total:** No details provided
2	Brown, J., Fowler, S., & Mason, T. M. (2023). **Nurse residents' legacy letters: A qualitative analysis**.	Nurse residents' experiences at cancer institute and advice to next group of residents	Qualitative Letters	Thematic analysis	There were 73 legacy letters in an existing database on the centre's intranet	**Per participant:** No details provided **In total:** 73 letters in database, 30 letters randomly selected and used.
3	Mawdsley, A., & Willis, S. C. (2023). **Academic resilience in UK pharmacy education–a pilot study applying love and break up letters methodology.**	The lived experience of pharmacy students	Multimethod Focus groups Letters	Thematic Analysis	Purposively, students were invited to take part in a pilot study with a love a break up letter writing task	**Per participant:** 1 letter, but one participant wrote two (one break up and one love letter) **In total:** 8

4	Day, M. C., Hine, J., Wadey, R., & Cavallerio, F. (2023). **A letter to my younger self: using a novel written data collection method to understand the experiences of athletes in Chronic Pain.**	Experiences of athletes in chronic pain	Qualitative Letters	Dialogical narrative analysis (DNA)	Criterion based purposeful sampling (i.e. to select information-rich cases who met the aims of the study). Letter writing task for study.	**Per participant:** 1 **In total:** 21
5	Burry, K., Beek, K., Worth, H., Vallely, L., & Haire, B. (2023). **Framings of abortion in Pacific Island print media: qualitative analysis of articles, opinion pieces, and letters to the editor.**	Attitudes to abortion in pacific island print media.	Multimethod Articles, opinion pieces, and letters to the editor The different types of texts were analysed together.	Inductive thematic analysis	Existing letters available online. We selected the newspapers in this analysis based on the availability of online content published in English.	**Per participant:** N/A **In total:** 246 articles, opinion pieces, and letters that cover the topic of abortion Proportion of letters not described.
6	Schmitz, H. P., Mitchell, G. E., & McCollim, E. M. (2021). **How billionaires explain their philanthropy: A mixed-method analysis of the giving pledge letters.**	Philanthropy of billionaires.	Mixed method 6 stepped analysis including inductive analysis and	Content analysis	Billionaire pledge letters	**Per participant:** 1 **In total:** 187

			statistical analysis.			
7	Kilgore, C. D., Lehmann, P., & Voth Schrag, R. (2019). **Discourse after a batterer intervention program: A qualitative analysis of "Letters from the future".**	Batterer intervention programme	Qualitative Letters	Grounded theory approach to content analysis Narrative Analysis	A writing assignment completed at the end of a solution-focused voluntary batterer intervention program.	**Per participant:** 1 **In total:** 44
8	Perrot, S., Launay, A., Desjeux, D., & Cedraschi, C. (2017). **Pain patients' letters: The visit before the visit–A qualitative analysis of letters from patients referred to a tertiary pain center.**	Letters from patients referred to a tertiary pain Center.	Qualitative Letters	Content analysis Semantic analysis	Purposive sampling Spontaneous letters from patients referred to a tertiary pain center.	**Per participant:** 1 **In total:** 42
9	Jensen, L. (2014). **User perspectives on assistive technology: a qualitative analysis of 55 letters from citizens applying for assistive technology.**	Danish citizens applying for assistive technology	Qualitative Letters	Deductive content analysis Inductive thematic analysis	Naturally occurring data in the form of 55 letters from 33 Danish citizens applying for assistive technology were used.	**Per participant:** 55 letters from 33 persons **In total:** 55

10	Cahalane, H., Parker, G., & Duff, S. (2013). **Treatment implications arising from a qualitative analysis of letters written by the nonoffending partners of men who have perpetrated child sexual abuse.**	Treatment Implications Arising From a Qualitative Analysis of Letters Written by the Nonoffending Partners of Men Who Have Perpetrated Child Sexual Abuse	Qualitative Letters	Thematic analysis	Participants were recruited from a 16-week group for Female nonoffending partners in a community forensic psychology service. Letters written as a therapeutic task were used as the data source.	**Per participant:** 1 **In total:** 9
11	Zannini, L., Cattaneo, C., Brugnolli, A., & Saiani, L. (2011). **How do healthcare professionals perceive themselves after a mentoring programme? A qualitative study based on the reflective exercise of 'writing a letter to yourself'.**	Participants responses to a reflective practice exercise about a mentoring programme	Qualitative Letter	Phenomenological-hermeneutic analysis	Participants who attended a mentoring/preceptoring programme	**Per participant:** 1 **In total:** 27
12	Furman, R., & Shukraft, A. (2007). **A qualitative study of letters to President**	The experiences of mental health consumers and their families	Qualitative Letters	The author analyzed the data for themes using traditional open	Archived letters written to the president in response to proposed mental health legislation.	**Per participant:** N/A **In total:**

	Kennedy from persons with mental illness and their families: Using the research poem in policy oriented research.			and axial coding methods. Data was presented in the form of three types of research poems: free verse, the pantoum, and tanka.		Files consisted of one hundred and seventeen letters to President Kennedy. A total of 20 letters met the criteria. From these letters, a subset of six was chosen to be analysed.
13	Timmis, M. A., Pexton, S., & Cavallerio, F. (2022, December). **Student transition into higher education: Time for a rethink within the subject of sport and exercise science?**	Aspects supporting or hindering transition into higher education.	Qualitative Letters	Reflexive thematic analysis. Composite letter	Students were invited to participate in study and complete a letter writing task.	**Per participant:** 1 **In total:** 58
14	Abnett, H. (2023). **Epistolizing accountability: a critical exploration of INGO annual report leaders' letters.**	How International non-governmental organisations (INGOs) communicate their activities and achievements.	Qualitative Letters	Reflexive Thematic Analysis.	This study took a purposive sample of 39 INGOs that published one or more leaders' letters within their Annual Reports and Accounts.	**Per participant:** N/A **In total:** 90
15	Hänninen, V., & Sools, A. (2022).	Cultural story models used by lay people in Finland	Mixed method Letters	Narrative analysis	Letters written for study. Convenience sampling	**Per participant:** 1 **In total:**

	Cultural story models in making sense of a desired post-corona world.	and Greece to make sense of desirable personal and societal changes in light of the corona pandemic	Survey			67
16	Gross, J., Davids, T., Sools, A., & Saghai, Y. (2023). **Covid-19 and the politics of hope: A comparative analysis of Greek and Ecuadorian letters from a desired post-pandemic future.**	Do personal imaginations of a desirable post-Covid future express hope, and if so, in what ways is this hope political?	Qualitative Letters	Data analysis software Thematic analysis	Letter written for study	**Per participant:** 1 **In total:** 105
17	Cahalane, H., & Duff, S. (2018). **A qualitative analysis of nonoffending partners' experiences and perceptions following a psychoeducational group intervention.**	The experiences and needs of nonoffending partners (NOPs), whose partners have perpetrated child sexual abuse (CSA)	Qualitative Letters	Thematic analysis	Participants were recruited from a 16-week psychoeducational group for female NOPs in a community forensic psychology service As a therapeutic task, group members write a letter to their partner at the beginning and end of the group.	**Per participant:** 1 **In total:** 12

18	Laughey WF, Brown MEL, Dueñas AN, et al. **How medical school alters empathy: Student love and break up letters to empathy for patients.**	Understand how students feel about empathy for patients by the time they reach the senior years of medical school.	Multimethod Letters and focus group Focus group transcripts and love and break up letters were analysed together.	Reflexive thematic analysis	Letters were written for the study.	**Per participant:** 2. A love and a break up letter to empathy for patients **In total:** 40
19	Sools, A. M., Tromp, T., & Mooren, J. H. (2015). **Mapping letters from the future: Exploring narrative processes of imagining the future.**	To explore the human capacity of imagining the future	Qualitative Letters	Narrative analysis Content analysis Comparative analysis	Letters were written for the study	**Per participant:** 1 **In total:** 480
20	Duff, S. (2010). **Exploring criminogenic need through victim apology letters: An interpretative phenomenological analysis.**	Issues of criminogenic need	Qualitative Letters	Interpretative phenomenological analysis	The research herein examines the pre treatment apology letters of men who have offended against children and who have attended for treatment at a community forensic service.	**Per participant:** 1 **In total:** 26

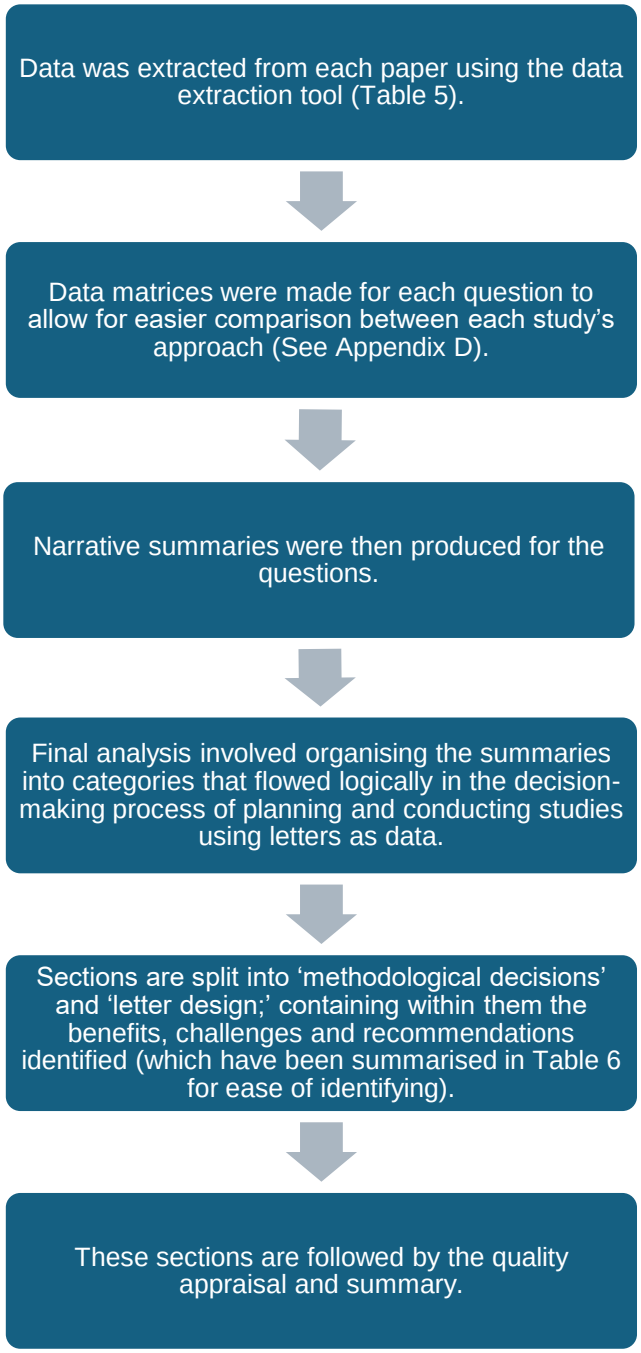
21	Duff, S. (2011). **Exploring criminogenic need through victim apology letters II: an IPA analysis of post-treatment accounts of offending against children.**	Post treatment apology letters of men who attended a community-based introductory sex offender treatment programme	Qualitative Letters	Interpretative phenomenological analysis	The current research focuses on post-treatment apology letters.	**Per participant:** 1 **In total:** 26
22	Webster, S. D., & Beech, A. R. (2000). **The nature of sexual offenders' affective empathy: A grounded theory analysis.**	The nature of sexual offenders' affective empathy	Qualitative Letters	Grounded theory analysis	Residential treatment program for child Abusers. Each participant was issued instructions to complete a victim apology letter as part of their therapeutic program.	**Per participant:** 1 **In total:** 31

2.6 Synthesis of findings

Analysis and synthesis of data extracted from the included papers followed a constant comparative method drawing on the method described by Gentles et al. (2016) in Figure 4.

Figure 4

Constant comparative methodology for data analysis and synthesis



2.6.1 Methodological decisions.

2.6.1.1 Design.

The papers in the review included a range of research method designs, most of which employed a qualitative design, utilising letters as the data set. Two studies utilised a mixed-methods design (Hänninen & Sools, 2022; Schmitz et al., 2021) and three studies employed a multi-method design (Burry et al., 2023; Laughey et al., 2021; & Mawdsley, & Willis, 2023).

Within the mixed-method designs, alongside the qualitative analysis of letter data, one study used a survey as a data collection method (Hänninen & Sools, 2022) and the other utilised a statistical analysis programme (latent class analysis) to quantitatively analyse the letter data (Schmitz et al., 2021). Two of the multi-method studies collected focus group data alongside letters, which were then qualitatively analysed together (Laughey, 2021; Mawdsley & Willis, 2023). The third multi-method study collected articles, opinion pieces and letters which were qualitatively analysed together (Burry et al., 2023).

Schmitz et al. (2021) stated that using statistical analysis alongside the qualitative analysis would provide a more concise and powerful understanding of the letters than what is feasible and interpretable with qualitative coding and summary statistics alone. However, the authors did not detail how the results from these two methods were integrated. Similarly, findings from the surveys conducted in Hänninen & Sools (2022) mixed-method study were not presented in the article, nor integrated with letter data. Moreover, the authors provided no rationale for the use of mixed methods (survey and letters).

Neither of the multi-method studies, in which they used focus groups and letter data, shared a rationale for the use of two qualitative data collection methods or how

they came to a decision to analyse both data sets together. However, they the authors did note several important benefits when using letters in conjunction with focus group methodology. Firstly, in the design of this study, participants wrote a letter before attending a focus group in which they shared the letter with the group at the beginning. The authors reflected that this format allowed all group members to have an initial voice, mitigating a limitation of focus groups, in which quieter members may be over-shadowed by talkative ones. Secondly, the authors stated that reading the letters aloud can act as an icebreaker for the discussion to follow. Finally, they described that the letters supplemented the focus group transcripts, providing increased quantity of data for analysis (Laughey et al., 2021). Whilst this paper did not discuss this in relation to quality, it appeared there is the possibility for increasing both quality and quantity of the overall data set when combining letter data with another form a data collection. This was supported in two studies where they noted that if letters are found to be brief, focused or with limited ability to interpret findings, letters could be combined with other methods such as interviews, focus groups, ethnography, and social media analysis to allow for a richer understanding of experiences (Brown et al., 2023; Gross et al., 2023). Furthermore, utilising letters alongside a focus group may improve data gathered within the group setting, due to the ability of the letters to support engagement (Laughey et al., 2021).

The multi-method study that used articles, opinion pieces and letters analysed the data sets together, but shared that they expected to see different opinions and information in print media than in letters and opinion pieces. No further details were provided in how integrating the different texts impacted the analysis. However, this indicates that different textual data sources may be impacted by the intended audience, which should therefore be considered in line with research questions. This

is explored further in the sections “Source of letters” and “Nature of prompts/instructions”.

From the included papers, it appears that using letters as a standalone data set, or using them alongside another data collection method, or type of analysis, appears to be feasible. There could be benefits to overall data quality and quantity by combining letter data with another method of data collection. However, overall, there were scant details surrounding the use of mixed and multi-method research in the papers identified in this review. In future it would be helpful for researchers utilising letters within mixed or multi-method design to consider and detail the rationale for this, because factors such as the philosophical foundations, integration of data, validity, and connections of different stages of the research process may differ depending on the design chosen (Creswell & Clark, 2023).

2.6.1.2 Epistemological stance.

Only six of the 22 papers stated an epistemological stance. These included critical feminist (Burry et al., 2023), social constructionist (Cahalane et al., 2013; Cahalane & Duff, 2018; Day et al., 2023 & Timmis et al., 2022;) and constructivist (Laughey et al., 2021).

Two studies provided a broad rationale for their epistemological stance, but this was not discussed in relation to letter writing; Timmis et al. (2022) described that social constructionism (i.e., knowledge is constructed and subjective) was used as it was in line with the aim of understanding students’ experiences. Day et al. (2023) stated that their study was underpinned by constructionism, which aligned with their narrative methodology; they described that narratives are the cultural and social resources from which people construct their personal stories.

Only one paper discussed their epistemological stance in relation to letter writing (Cahalane & Duff, 2018). They described that the letters would contain women's own language, rather than being potentially shaped by interview questions, and as such was in line with a social constructionist framework.

To summarise, limited details were included regarding the epistemological stance of papers included, and how this may interplay with using letters as data. Without this information specific recommendations regarding epistemological stance cannot be made. However, taking into consideration wider understandings of epistemological framework and qualitative analysis of textual materials, it could be anticipated that several epistemological stances could be appropriate depending on the intended interpretation and use of the data. For example, a critical realist approach would allow a researcher to acknowledge a reality independent of perceptions, but also takes into consideration how subjective experience shapes understandings of that reality; as such this approach would allow a researcher to understand how individual experiences may shape the letters produce, and how their own subjectivity will impact on the analysis of the letters (McEvoy & Richards, 2003). Whereas a post structural framework for example, is concerned with how knowledge and meaning are produced through discourse and language, so instead may focus on deconstructing the text to examine power or cultural discourses (Strega, 2015). It will be important for researchers utilising letter data in future to ensure to draw on wider understandings of epistemology and qualitative research and align the epistemological stance with the other aspects of research methodology.

2.6.1.3 Source of letters.

Sources for the letters utilised in the analysed articles can be broadly split in to three categories:

1. *Letter written as part of the study*: seven papers required participants to complete a letter writing task write as part of the study (Day et al., 2023; Gross et al., 2023; Hänninen & Sools, 2022; Laughey et al., 2021; Mawdsley, & Willis, 2023; Sools et al., 2015 & Timmis et al., 2022).
2. *Letter as part of a routine treatment intervention or program:* eight studies utilised letters that were written as part of a routine treatment intervention or program.
3. *Archived letters***:** seven studies utilised letters that existed in archives and databases that had come from more naturalistic sources, such as spontaneous letters to a pain service (Perrot et al., 2017) or existing fan letters (Cummings & Gruenert, 2011).

Although there was much variability in the quantity of data used between papers, this did not appear to correspond to the source types described above (see 'Number of Letters Used' for more detail). However, when considering the quality of data across the sources of letters, challenges around biases to the data were noted for both pre-existing letters and those written for an intervention. Regarding pre-existing letters, Burry et al. (2023) noted that the data may not be fully representative of the full scope of views as the author has less control over the participant pool and the data available. In letters tasked to participants during interventions, participants may modify what they write in anticipation of having it read by practitioners (Kilgore et al., 2019), or with the concern it may have an impact on their care (Cahalane et al., 2013). However, strengths noted around using naturalistic data were that pre-existing letters can help produce participant responses uninfluenced by the researcher (Perot et al., 2017), and that they may help to capture views from populations who are less likely to respond to more conventional data collection

techniques such as surveys or interviews (Schmitz et al., 2021). However, when the collection or generation of new data is required, Duff (2011) described that letters may allow participants to freely write an account of the topic of interest, which may be more directive than naturalistic data.

When comparing the three types of letter sources identified in the articles, it seems that utilising archived or pre-existing may letter data may reduce the practical and administrative tasks for the researcher, and potential burden to participants. However, designing a study in which participants engage in a specific letter witing task may allow researchers more control over what is asked, and how it is asked; this could have the benefit of producing more directed data where required.

In conclusion, the papers analysed suggested the quality, but not quantity, of data produced varies between letter sources. As such, it is important for researchers to weigh up the strengths and limitations of utilising different letter sources, taking into consideration the question(s) of the research and the data therefore required.

2.6.1.4 Aims, experience studied and rationale for letters.

The aims of studies and condition/experience being studied were heterogenous. For example, the aims ranged from informing the prevention of AIDS (Cummings & Gruenert, 2011) through to investigating discourse about billionaire philanthropy (Schmitz et al., 2021). The condition and/or experience being studied stretched from athletes with chronic pain (Day et al., 2023) to post treatment apology letters written by men who attended a community-based sex offender treatment programme (Duff, 2011).

Only two studies made links between the rationale to use letters and experience or population in the study. Kilgore et al. (2019) suggested that letters may help reveal participants beliefs and values. In the context of their study, which

explored letters written as part of a ‘batterer intervention programme’, they felt that letters may also reveal something about participants future actions. Similarly, Duff (2010) explored factors relating to criminal activity, suggesting that letters can be considered as accounts of an individual’s understanding of the world and will hold information regarding risk factors surrounding these individuals. This proposes that there could be value to utilising letters in research to support a better understanding of individuals experience. In gaining a deeper understanding of an individual or shared experience, improved support can then be developed or offered.

Other broader reasons for using letters included: allowing the participant more time for contemplation and reflective description compared to other ways used to collect qualitative data (Day et al., 2023), participants might be more honest in letters and more likely to use their own language compared to an interview, aiding participants to share their feelings (Laughey et al., 2021), and allowing problems to be externalised and provide an opportunity to learn from experience (Timmis et al., 2022).

Therefore, when looking at the rationales to use letters in data collection, it is important to include consideration of research ethics (the impact of data collection on participants and maximising output from the data available) and the potential benefits that can come from the research (reduction of researcher bias). Although several studies used letters as data without explaining the decision making around this, some studies did provide broader rationales for the use of letters (e.g., uncovering participants’ beliefs or intentions).

However, rationales had significant variation, and most often were often not discussed in relation to the population or experience of the individual(s)/group being studied. As such, further research may be beneficial in determining which

populations letters as a data source may be most appropriate for. Furthermore, when using letters, future researchers should provide their considerations and justification for using this data source type in relation to the specific population in the study. In doing so, further evidence for the acceptability and feasibility of letter use within specific populations can be gained, aiding more informed consideration of letters as a data source in future research.

2.6.1.5 Qualitative analysis used.

When reviewing the qualitative analyses used among the articles, it was evident that a wide range of analyses had been utilised. Many papers used either thematic analysis (Brown et al., 2023; Burry et al., 2023; Cahalane et al., 2013; Cahalane & Duff, 2018; Gross et al., 2023; Mawdsley & Willis, 2023) or RTA (Abnett, 2023; Laughey et al., 2021; Timmis et al., 2013). A lesser number of papers used dialogical narrative analysis (Day et al., 2023), content analysis (Schmitz t al., 2021), grounded theory approach to content analysis (Kilgore et al., 2019), content and semantic analysis (Perrot et al., 2017), a mix of deductive content analysis and inductive thematic analysis (Jensen, 2014), phenomenological-hermeneutic analysis (Zannini et al., 2011), axial coding (Furman & Shukraft, 2007), narrative analysis (Hänninen & Sools, 2022), combined narrative, content and comparative analysis (Sools et al., 2015), interpretative phenomenological analysis (IPA) (Duff, 2010; Duff, 2011) and grounded theory analysis (Webster & Beech, 2000). One paper did not clearly state the qualitative analysis used (Cummings & Gruenert, 2011).

A small number of papers described a rationale for choice of analysis in relation to using letter data. For example, Duff (2010) described that IPA was chosen as it focuses on the way in which an event is experienced and recounted by the individual. Furthermore, it seeks to explore the understandings, perceptions and

views of individuals, which the author also suggested letter writing is well suited to. Alternatively, Timmis et al. (2022) stated that thematic analysis (TA) was used as it is an analytical approach that allows researchers to identify repeated patterns in written data (Braun & Clarke, 2021), and therefore is an appropriate analysis to use on written letters. Day et al. (2023) employed dialogical narrative analysis (DNA) to analyse the letters, describing that this form of narrative analysis allowed authors focused on the relationship between the events being narrated and the event of narration. In doing so, the authors suggested that they could better consider the participants experience as a result of telling the story. Finally, Kilgore et al. (2019) described that they employed an inductive grounded-theory approach, which enabled them to draw out patterns in the letter content, rather than risk imposing predetermined discursive structures on the letters. Although there are similarities in this approach and TA chosen by Timmis et al.(2022), a grounded-theory approach additionally allowed the authors to generate a theory directly from the data.

One practical factor to consider in relation to the data analysis, is when to exclude data. In one study it was noted that letters in which participants did not follow the instructions were excluded from the analysis (Kilgore et al., 2019). This indicates that researchers may need to make some decisions about what data will be acceptable to include, and reasons for exclusion. This may be linked to wider research aims and epistemology; for example, some researchers may be more concerned with participants responding to specific instructions, whereas other researchers may be more interested in what responses were invited in participants due to the instructions provided, and this could form part of the analytic procedure.

Recommendations for the analysis of letter data in future research were made. One recommendation was asking participants to title their letters with one

take home point to allow letters to be grouped by theme (Brown et al., 2023). A further suggestion was that researchers should pay attention to explanations that are rarely or not mentioned in the letters, identifying what remains unsaid in the discourse (Schmitz et al., 2021). Both ideas indicate interesting and novel ways to engage with the qualitative data collected.

To summarise, despite only a small number of studies providing reasoning for the chosen analysis, it seems that many types of qualitative analysis can be utilised. The decision regarding which analysis to use for letter data will largely depend on the research aims and objectives, which is in line with other types of qualitative data analysis (Busetto et al., 2020). However, it will be important for researchers to consider what kind of results are required and the type of findings they would like to share, for example, choosing TA would allow for the exploration of data to remain broad (Braun & Clarke, 2006), whereas IPA would allow for a detailed examination of individuals lived experiences (Alase, 2017). Decisions about analytical approach should therefore be made by researchers based on researcher epistemology, research question and study aim.

2.6.1.6 Findings.

Several strengths, limitations and recommendations for future research were identified when considering the results produced in letter research. Owing to letters being non-interactive (between the participant(s) and the interviewer/researcher(s)), some studies concluded that it was difficult to explore original meanings (Perrot et al., 2017), or clarify ambiguities (Cahalane et al., 2013) in what participants had written. There is also the possibility that findings will be brief (Brown et al., 2023). A remedy for these factors could be the correspondence approach where researchers write to participants with a series of letters sent back and forth (Harris, 2002).

In one article it was mentioned that all grammatical mistakes in the original letters were kept in the quotes for the paper to represent a true reflection of the original letters (Duff, 2010). Researchers may want to consider how this approach fits with their study design, ethics and aims. For example, if opting to utilise a discourse analysis it may feel more important to represent letters exactly as they were written, as the researcher may be concerned with the specifics of language used, such as grammar or vocabulary (Trappes-Lomax, 2004). This is in contrast to TA, which looks for patterns across the data (Braun & Clarke, 2006).

Several papers detailed the creative and reflective benefits letter writing offers. For example, by asking participants to think in hindsight or towards the future, researchers felt that this provided participants the opportunity to clarify meaning of the past and to find out about themselves (Day et al., 2023), rather than just share current and conscious beliefs in which an opinion poll might do. Furthermore, Laughey et al. (2021) described that love and break up letters call for creativity, encouraging the use of figurative language, metaphor, and poetry. Consequently, this method can elevate interest and engagement of participants and produce more colourful results. Furthermore, the authors also noted that the creative writing in letters communicates richer messages, which translates into richer data for analysis, and therefore a more engaging process for researchers.

Alongside the ability for participants to be more creative and produce rich data, there are many creative ways that the results from research utilising letters can be presented and shared. Furman and Shukraft (2007) presented their data in the form of three types of research poems. Once themes were identified, the researchers undertook the process of representing some of the observed themes in different poetic forms. They suggested the decision making that goes into creating

the research poems encourages an intimate familiarity with data. Two of the articles in the review utilised a composite letter; a collective letter written by the researchers which is an amalgamation of participant voices and quotes. Day et al. (2023) presented a collective letter in the results section to share the narrative themes that were evident in the data collected, and Timmis et al. (2013) developed and utilised a composite letter to disseminate findings to the community researched as a pastoral care resource. It was also suggested that letters could be disseminated to a range of readers, such as healthcare professionals or individuals from the community researched. Ensuring appropriate consents for future use, these can become as an accessible source for learning or source of support (Day et al., 2023).

In summary, although there is the risk of collecting brief findings, utilising letter data appears to come with a wealth of strengths when considering the impact on how the findings can be sought and shared. Utilising letter data may create increased engagement for both participants and researchers, both within the letter writing process, and in the analysis of findings. Furthermore, letter data provides researchers the opportunities for creative dissemination, and as such may create novel and memorable experiences for those receiving the findings.

2.6.2 Letter design.

2.6.2.1 Who or what the letter is addressed to.

There was variability among the articles regarding who or what the letters were addressed to. In some articles the letters were written to participants themselves (Day et al., 2023; Hänninen & Sools, 2022; Kilgore et al., 2019). In other articles letters were written to others, such as a partner (Cahalane et al., 2013; Cahalane & Duff, 2018), victim (Webster & Beech, 2000), or organisation or newspaper (Burry et al., 2023). Some researchers asked participants to write to a concept, for example,

to their own resilience (Mawdsley, & Willis, 2023) or empathy (Laughey et al., 2021). It seems that asking participants to write to a concept may require a level of creativity or imagination that may not be required for example when writing to others, as this may feel more familiar. It should be considered that these more creative ways to write may feel more acceptable to some individuals than others.

In summary, decisions regarding who letters were addressed to appeared to be related to readily available data, pre-existing intervention, or an attempt to explore a particular concept or experience from a certain perspective

2.6.2.2 Nature of the prompts/instructions.

Across the articles there was variability in the approach to providing instructions for the letter writing tasks. In the research using pre-existing letters, instructions to participants about how to write their letters were not required (Abnett, 2023; Burry et al., 2023; Cummings & Gruenert, 2011; Furman & Shukraft, 2007; Jensen, 2014; Perrot et al., 2017; Schmitz et al., 2021), and as noted in the section “Source of letters”, this may contribute to more naturalistic data. However, when designing future studies in which the letters are more naturalistic and therefore instructions are not given, it may be important to contemplate who the letters were expected to be read by or addressed to, and how this may also shape the resulting letters.

For the studies where letters were written as part of an intervention/treatment programme, or where letters had been written as a task for the study, there was much variation in the type of letter writing task and instructions used. These articles also provided a varying level of detail regarding the instructions used for the letters, with one study providing no details on the specific prompts/instructions given to participants outside of participants being directed to write a letter to themselves (Zannini et al., 2011).

Some studies utilised detailed letter writing instructions, whereas other provided instructions with little guidance. One rationale for providing little guidance regarding the content, length, or style of the letter was to best ensure the letter represented how the participant currently understood themselves and their offending (Duff 2010; Duff, 2011). Others also described that the brief was deliberately kept open to invite a range of imagined responses (Gross et al., 2023).

Other researchers gave several prompts in succession, with each prompt encouraging participants to think about aspects of their writing. For example, Day et al. (2023) first encouraged participants to think about a specific time point in their life, then to think about what they would like the letters to say, followed by what they would tell themselves about the future. Hänninen and Sools (2022) also provided a few successional prompts, including sensory prompts such as what they participant may see, feel, and hear in their imagined future. The authors used an elaborate six staged instruction to encourage narrative writing that was experiential and detailed.

In addition to considering prompts, specific letter writing exercises can also be used. Three types of letter writing exercises were utilised across multiple papers. These were ‘love and break up’ letters (Laughey et al., 2021; Mawdsley, & Willis, 2023), ‘older wiser self’ letters (Day et al., 2023; Timmis et al., 2022) and ‘letters from the future’ (Gross et al., 2023; Hänninen & Sools, 2022; Kilgore et al., 2019; Sools et al., 2015). Love and break up letter methodology (LBM) is where participants are asked to write a love letter and/or breakup letter (Laughey et al., 2021). Laughey et al. (2021) stated that LBM is a creative way to understand participants' relationships with the concept under discussion, allowing for expression of affective domains. Whereas the ‘older wiser self’ exercise encourages participants to draw on what has been learned over time (Day et al., 2023). Day et al. (2023) noted that letters

addressed to the self, do not need to be understood by an ‘outsider’ and as such, participants may write in a way that is more intuitive and which resonates with their own language. Lastly, the ‘letter from the future’ exercise asks participants to imagine a time in future and write back to themselves from this time (Kilgore et al. 2019).

It was noted that, alongside broader instructions around how to write the letter, other encouraging information could be offered to participants. For example, one paper described providing participants with, instructions to not worry about grammar, spelling, or “getting it right” (Day et al., 2023). These additional instructions may help participants feel more comfortable to engage with the writing process. Additionally, Mawdsley, & Willis (2023), provided an example letter before participants were asked to write their own. In doing so, this may help to build participant confidence by providing a better understanding of how to write a letter, and desired content, without explicit instructions and/or limitations. However, this may also shape the data based on what is included in the letter.

Many challenges related to providing letter writing instructions were noted. Sools et al. (2015) stated that unsupervised letter writing does not afford the researcher the opportunity to check or confirm that participants have followed the instructions, resulting in no guarantee that the required data will be received. To mitigate this risk some studies opted to provide more in-depth instructions to support narrative writing by (Hänninen & Sools,2022). However, as described by Hänninen and Sools (2022), a high participant dropout rate may result from using elaborate narrative instructions. This indicates that there is a difficulty in balancing the instructions to make them clear enough to be followed, and not too detailed that they become off putting or unclear. Additionally, the type of instructions provided may impact the data, for example, Laughey et al. (2021) stated that love and break up

letters instruct participants to focus on polar opposites. This may result in collecting only dichotomous data, limiting the breadth of content or constraining participants to write in a certain way.

When considering the use of letter writing prompts and instructions, it is necessary to consider what the letter will represent and whether consideration of this is necessary for analysis. It is also important to consider how being too prescriptive, or not directive enough, might affect engagement with the task and affect attrition rates.

2.6.2.3 Number of letters used.

The total number of letters used across the studies ranged from eight (Perrot et al., 2017) to 480 (Sools et al., 2015). Table 7 below shows the range of letters per study used according to letter type.

Table 7

Range of Letters Used (number of letters per study)

	Lower limit	Upper limit
Letters from existing databases/archives	6 (Furman & Shukraft, 2007)	187 (Schmitz et al., 2021)
Letters for the study	8 (Perrot et al., 2011)	480 (Sools et al., 2015)
Letter as part of an existing treatment/programme	9 (Cahalane et al., 2013)	44 (Kilgore et al., 2019)
Multimethod study	246 sources used* (Burry, 2023) *proportion of letters was not described.	

In the majority of papers where participants wrote a letter for the study or as part of a treatment/intervention a single letter was written by each participant. Exceptions to this were studies that utilised LBM. For example, Mawdsley and Willis (2023) instructed participants to write a love and/or break up letter. Most participants chose to write only one break up letter, with one participant writing two letters: one

love letter and one break up letter (Mawdsley & Willis, 2023). Participants also wrote two letters, both a love and break up letter in the study conducted by Laughey et al. (2021), which similarly utilised LBM. In one paper using naturalistic letters, 55 letters were written by 33 people (Jensen, 2014). In the other papers where letters were used from existing archives it was not noted whether multiple letters were used from the same person.

Overall, there was great variability in the amount of letters used between the studies, and the rationale for the total number of letters used appeared to be pragmatic, such as using ‘the amount that had been submitted’ (Schmitz et al., 2021) or the number of available letters from people attending a program (Cahalane et al., 2013; Cahalane & Duff, 2018; Duff, 2010; Zannini et al., 2011). Others described using a suitably sized data set for the purpose of their analysis, but no further details were provided on how this decision was made (Gross et al., 2023). Some studies utilising pre-existing letters described choosing a subset of letters by using a random generator (Brown et al., 2023), or reducing letters using a selection criterion (Furman & Shukraft, 2007), but did not detail reasons for this.

One study discussed the number of letters collected and analysed in relation to sampling and saturation. Here they described using a pragmatic and flexible approach to sampling where a participant sample was included to ensure that the sample was diverse enough to include various experiences (Perrot et al., 2017). However, data saturation may not always be applicable when utilising letters dependent on factors such as epistemological stance and analysis method (Braun & Clarke, 2021; Low, 2019).

In summary, the papers in the review indicate that it is feasible to conduct studies with a small number of letters, ranging to a much larger data set. Overall, the

papers that discussed the reasoning for the sample size/number of letters discussed more general methodological and procedural rationales, rather than specific discussions about letter data in relation to sample size. It would be important for researchers to consider this as this will be linked to other factors such as epistemological positions and types of analysis use. This would also need to be considered in relationship to the length of letters, and the depth of response needed for the question posed of the type of analysis undertaken.

2.6.2.4 Format.

Letters can be written to researchers in different formats. The studies included in this review evidence this with handwritten letters (Perrot et al., 2017; Zannini et al., 2011;), as well as those typed on the computer or typewriter (Perrot et al., 2017). Several studies did not detail the format of the letters. One study using pre-existing letters noted that about half were handwritten and half were typed (Furman & Shukraft, 2007), indicating that participants may prefer a particular format and should therefore be given choice in the design of a study to support inclusivity and preference. However, this may result in a higher processing burden for researchers.

In addition to there being different letter writing formats, means of sending letters to researchers also varied. One article documented that letters were received via email or post, and that the option to post letters back was given to allow participants to remain anonymous (Day et al., 2023). Two studies utilised a web-based tool for participants to write and submit their letter (Hänninen & Sools., 2022; Sools et al., 2015), offering a more streamlined process to both participants and researchers.

Two articles, where letters were written as part of a program, described the practicalities of where participants wrote their letters and what happened to them

afterwards. In one study, the participants of the group wrote their letters at home and brought them to the group to initiate discussion (Duff, 2011). Alternatively, Webster and Beech (2000) noted that participants were seated privately in a room while they constructed their letters. On completion, these letters were recorded onto a videotape, and then transcribed. It is unclear in the article why the letters were recorded; however, it could be anticipated that if the participants were asked to read aloud their letters whilst being recorded this could be a further method to contribute to the data collected, by providing additional information about participants tone or emotion.

One article described that at the end of the study, participants were given the choice to give their letter to the course organizers or to keep it for themselves (Zannini et al., 2011). This is important to consider for future research, as the process of writing a letter may involve personal stories and emotions, and as such participants may have a sentimental connection to the letter or wish to keep it as a record of their thoughts and feelings at the time.

In summary, it is feasible to use letters that have been hand or electronically written, for participants to send letters in the post, or to use an online platform. Overall, discussion around pros and cons of different letter formats and submission types was lacking from included papers. Similarly, the majority of papers did not discuss the important ethical consideration of what happens to the letters following the research. Future researchers should consider whether letters should be mailed back to participants or processed in the same way as interview data, ensuring the participants involved in the study are informed.

2.6.2.5 Length of time to complete.

Four out of seven articles where participants were instructed to write a letter for the study included details of how long they were given to do this. Two of these stated participants were given 30 minutes to write their letter (Laughey et al., 2021; Mawdsley & Willis, 2023) and one study gave participants 20 – 30 minutes (Timmis et al., 2022). Finally, whilst Hänninen & Sools (2022) stated that participants could log out of online latter writing platform at any time and continue writing later, they did note that completion of the survey and letter typically took between 20 and 60 min. They surmised that the variation noted was dependent on how elaborate participants were with their writing.

Although some studies noted the amount of time participants were given to write a letter, no rationales were provided. Due to the limited information, it is therefore hard to conclude how the length of time provided could impact on inclusivity or attrition. Future studies should include considerations surrounding how long participants should be given to write a letter, taking into accounts factors such as learning needs, styles of writing, practicalities and the type of data required.

2.6.2.6 Length of letters.

The information regarding the length of letters was limited in the articles reviewed. However, in those that did provide this information, there was variability described in the length of the letters both within and between studies. Schmitz et al. (2021) reported an average length of 441.58 words (median of 400 words). This was similar to another study, which reported a median letter length of 483.5 words, with almost all letters being less than 1,000 words (Abnett, 2023). One study did not share the word counts but stated the length of the letters varied considerably from 10 hand-written lines to two pages using an Arial 10 font (Perrot et al., 2017). Day et al.

(2023) described that participants were told there was no ideal length for the letter, and therefore set no limitations around this to encourage participants to write freely. In contrast, Hänninen & Sools (2022) limited the sample of letters once they had been received and used only those letters containing at least 300 words. Although they did not state a rationale this decision, it may indicate they were considering the richness of data received. However, this exclusion criteria may risk excluding data from individuals who opted to write shorter letters for factors such as time constraints, writing ability and emotional distress, leading to bias or misrepresentation.

2.6.3 Participation in studies utilising letter data.

Several studies indicated that the creative writing abilities and individual needs of participants can impact the data collected via letters. For example, participants' ability and willingness to articulate their experiences in writing will be influenced by their literacy levels (Cahalane et al., 2013). Duff (2010) stressed that it is important to consider how this will impact letter data collected and analysed, as this may exclude some individuals from taking part or limit the data collected from an individual.

Mawdsley & Willis (2023) and Perrot et al. (2017) suggested that letter writing may lead to gender bias or misrepresentation, finding a higher number of female participants writing and sending letters, indicating that communication by letter is perhaps easier or more appealing for participants identifying as female than male. However, Mawdsley and Willis (2023) also noted that the wider population drawn from for their study was predominantly female, suggesting that their data pool may be representative of this. As such, the conclusions drawn around gender and letter writing may therefore not be accurate and would need to be further explored. The importance here is to consider whether the letter methodology is acceptable and

accessible to the participants for whom the study is aimed at, which could be explored by inviting individuals with lived experience to consult on the project.

Some articles described benefits to participating in letter writing research that extended outside of the aims of the studies; this included experiencing the letter writing process as cathartic and achieving an improved sense of wellbeing were described (Mawdsley & Willis, 2023; Day et al., 2023). These factors could provide additional motivations for participants to take part in research. However, this may not be the experience of all participants, due to the topic under exploration and their own personal experiences, and as such should be sensitively considered.

2.7 Quality appraisal of studies

Although this review did not aim to examine the quality of empirical evidence found in the studies, it was still deemed important to use quality assessment tools to give an overview of the strengths and limitations of the papers in the review. In doing so, this appraisal could help to inform improvements in the methodological use of letters in research in future.

Due to a diverse range of methodological designs used in the reviewed studies, two different appraisal tools were utilised. The CASP qualitative studies checklist (Critical Appraisal Skills Programme, 2024) was used to assess the 17 qualitative studies and the three multi-method studies, as to date a multi-method appraisal tool has not been developed. The Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) was used to assess the quality of the two mixed methods studies. The MMAT was chosen as, unlike the CASP, it facilitates the appraisal of mixed methods studies (Hong et al., 2018). The MMAT allows a reviewer to consider the quantitative and qualitative characteristics of a study, and how to bring these

together to evaluate the paper as a whole (Hong et al., 2018). The CASP is a widely used tool which is endorsed by both the Cochrane Qualitative and Implementation Methods Group and the World Health Organisation and therefore appropriate for the purpose of the current review (Long et al., 2020).

The full quality appraisal tables for both the CASP and MMAT quality appraisals can be found in the appendix (See Appendix E, Appendix F). An overview of the quality appraisal can be found in Table 8 and Table 9. The key areas where limitations were observed and the salient details that are most informative for developing and improving the body of research using letters as data have been drawn from these tables and formulated in to one narrative below. To support readability, articles will be referenced in this section according to allocated numbers from Tables 8 and 9.

Table 8

CASP Quality Appraisal tool

	(1) Cummings, C. & Gruenert, S. (2011).	(2) Brown, J., Fowler, S., & Mason, T. M. (2023).	(3) Mawdsley & Willis. (2023)	(4) Day, M. C., Hine, J., Wadey, R., & Cavallerio, F. (2023).	(5) Burry, K., Beek, K., Worth, H., Vallely, L., & Haire, B. (2023).	(7) Kilgore, C. D., Lehmann, P., & Voth Schrag, R. (2019).	(8) Perrot, S., Launay, A., Desjeux, D., & Cedraschi, C. (2017).	(9) Jensen, L. (2014).	(10) Cahalane, H., Parker, G., & Duff, S. (2013).	(11) Zannini, L., Cattaneo, C., Brugnolli, A., & Saiani, L. (2011).	(12) Furman, R., & Shukraft, A. (2007).	(13) Timmis, M. A., Pexton, S., & Cavallerio, F. (2022)	(14) Abnett, H. (2023).	(16) Gross, J., Davids, T., Sools, A., & Saghai, Y. (2023).	(17) Cahalane, H., & Duff, S. (2018).	(18) Laughey WF, Brown MEL, Dueñas AN, et al. (2021).	(19) Sools, A. M., Tromp, T., & Mooren, J. H. (2015).	(20) Duff, S. (2010).	(21) Duff, S. (2011).	(22) Webster, S. D., & Beech, A. R. (2000).
1) Was there a clear statement of the aims of the research?	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
2) Is a qualitative methodology appropriate?	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
3) Was the research design appropriate to address the aims of the research?	YES	YES	CAN'T TELL	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	CAN'T TELL	YES	YES	YES	YES
4) Was the recruitment strategy appropriate to the aims of the research?	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
5) Was the data collected in a way that addressed the research issue?	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
6) Has the relationship between the researcher and participants been adequately considered?	NO	NO	NO	CAN'T TELL	CAN'T TELL	NO	NO	NO	NO	CAN'T TELL	NO	CAN'T TELL	NO	NO	NO	CAN'T TELL	NO	NO	CAN'T TELL	NO
7) Have ethical issues been taken into consideration?	CAN'T TELL	CAN'T TELL	CAN'T TELL	YES	CAN'T TELL	CAN'T TELL	YES	CAN'T TELL	YES	YES	NO	CAN'T TELL	NO	NO	YES	CAN'T TELL	NO	CAN'T TELL	YES	NO
8) Was the data analysis sufficiently rigorous?	CAN'T TELL	YES	YES	YES	CAN'T TELL	CAN'T TELL	CAN'T TELL	CAN'T TELL	CAN'T TELL	CAN'T TELL	CAN'T TELL	YES	CAN'T TELL	YES	YES	YES	YES	YES	YES	CAN'T TELL
9) Is there a clear statement of findings?	NO	YES	YES	YES	CAN'T TELL	CAN'T TELL	NO	CAN'T TELL	YES	CAN'T TELL	NO	CAN'T TELL	CAN'T TELL	CAN'T TELL	YES	CAN'T TELL	CAN'T TELL	YES	YES	YES

Table 9

MMAT Quality Appraisal tool

	(6) Schmitz, H. P., Mitchell, G. E., & McCollim, E. M. (2021).	(15) Hänninen, V., & Sools, A. (2022).
1. Are there clear research questions?	YES	YES
2. Do the collected data allow to address the research questions?	YES	YES
3. Is there an adequate rationale for using a mixed methods design to address the research question?	YES	CAN'T TELL
4. Are the different components of the study effectively integrated to answer the research question?	CAN'T TELL	NO
5. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	CAN'T TELL	NO
6. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	NO	NO
7. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	YES	NO

2.7.1 Evaluation of study quality based upon CASP and MMAT.

Critical appraisal of the 22 articles included in this systemic literature review indicated that the studies using letter writing as a sole, multi or mixed method of data collection provided clear research aims which were addressed with the data collected. Only three of the articles appraised failed to provide sufficient rationale for the research methods design (3, 15 and 18); in two out of three of multi-method studies there was no in-depth rationale as to why two types of qualitative data were employed in the design (3,18), and in one mixed-method study there was an unclear rationale for utilising both survey and letter data (15).

Only 50% (10 out of 20) of the qualitative and multi-method articles were found to have sufficiently rigorous data analysis. One of the multi-method study analysed did provide a rationale for the different qualitative data sets (5), whereas in both mixed-method studies it was unclear how the components were integrated and interpreted to answer the research question (6,15) (previously discussed further in section “Sources of data,”). Furthermore, any inconsistencies between quantitative and qualitative results in these two articles were not mentioned or addressed (6,15). These appraisal findings may suggest that the use of mixed method research that utilises letter writing alongside quantitative methods may produce results that require an elevated level of analysis compared to solely qualitative approaches.

An area in which a number of papers appeared to be lacking was discussion around any contradictory findings (1,2,3,5,7,8,9,10,11,12,13,14,15,17,18,19,21,22). Contradictions in findings in qualitative research are opportunities for deeper exploration and understanding and addressing contradictory findings demonstrates transparency in the research process. As such, future research utilising letters could aim to incorporate exploring contradictory findings within the analysis, to help demonstrate the richness and depth of data collected, and to show that this depth of data is collectable via letters.

Discussing contradictions in findings requires researchers to reflect on their own role and relationship to the research, however, this was another area where information was lacking. In most qualitative and multi-method papers the researcher did not share their own role or potential biases during formulation of the research question or data collection (1,2,3,4,5,7,9,8,10,11,12,14,15,16,17,18,19,20,21,22). Some authors demonstrated awareness of the importance of reflexivity by stating their positionality but did not explain how this may have subsequently impacted the

research question or data collection (5,13). Additionally, in many articles researchers did not critically consider their own role in the analysis process (1,3,5,7,8,9,10,12,13,14,15,16,17,19,20,21,22). In a small amount of papers reflexivity practices were noted, such as discussing preconceptions and reflecting on the topic, but did not provide further details in how this was taken into consideration or impacted the analysis of letter data (4,11,18,21). This is important to demonstrate in qualitative research more broadly to help mitigate bias and increase credibility (Olmos-Vega et al., 2023). This could be of particular interest in research using letters, as the inability to check the meaning of what is shared in a letter, may more easily lead to researchers drawing on their own assumptions and biases if not engaging in reflexivity practices.

Across the articles there was limited discussion around ethical issues in relation to using letters as data and conduct of the studies more generally. A few papers presented only superficial acknowledgement of ethical considerations by referencing that approval had been sought from an ethical committee (2,3,13,18). However, many papers did not include any information regarding ethical concerns (1,3,7,9,14,12,16,19,22). Only seven of the papers assessed using the CASP provided more detailed consideration of ethics outside of whether ethics had been sought from a committee. For example, Day et al. (2023) suggested that the letter writing method holds potential to evoke difficult memories, and it is important for researchers to consider how to protect the well-being of participants given that letters are written in a time and location to suit the participant, and therefore often not under the direct observation of the researcher. The authors suggested that clear information on support available must be given, providing sources of further support and referral networks. Day et al. (2023) also recommends individually responding to

letters that are submitted, instead of using a standardised debrief. They used a reflexive ethical approach (Smith & Sparkes 2014) where they responded in an adaptable and responsive way that paid attention to each unique situation. Three studies noted an ethical factor as part of the rationale for using pre-existing letters (10,14,17). For example, using letters that were already written as part of a group was felt to minimise the risk of causing unnecessary distress to participants (Cahalane et al., 2013; Cahalane & Duff, 2018). Duff (2011) stated that prior to any of the research taking place service users, who were potential participants, were given the opportunity to discuss the research, its potential usefulness, and how best to conduct it; these views were then incorporated into the design of the study. This indicates that patient or public involvement in the research process could be useful for studies utilising letters, to ensure that high quality and ethically sound research is produced.

Whilst the MMAT does not assess ethical considerations, the mixed-methods papers were also checked to see whether ethical considerations were noted. This was done as it was felt this may be of use to help guide researchers using letters in the future. One of the two mixed-method papers gave no mention of ethical considerations (6), with the other only briefly discussing factors such as consent and data management (15). In research using letters, there are specific ethical issues that need to be navigated, such as the distance from the researcher when letters are completed. This can limit the support that participants may require, especially when writing about emotive or traumatic subjects or events. It is therefore concerning that so few studies appeared to thoughtfully consider ethical issues around the use of letters and is strongly advised that future studies do so.

Many papers identified new areas of research (2, 3, 7, 8, 10, 12, 13, 14, 15, 17, 18, 19, 20, 21, 22). For example, one suggestion included determining why and when participants (knowingly or not) divert from the letter writing instructions which would help develop the letter writing method and improve the data received (19). This could be researched by providing a variety of different instructions and comparing results, or gleaning feedback on instructions from participants who have taken part in a letter writing task. A second suggestion was to explore the impact on individuals when reading the letters produced in a study. This was suggested in the context of nurse legacy letters (2); utilising the data output in the way could help to understand the impact of disseminating findings in this way.

Overall, the quality analysis has added to the prior synthesis detailed by highlighting the areas where limitations were identified and areas where improvements can be made when conducting studies utilising letter data. From the evaluation it would be most important for researchers to consider their role in analysis, think carefully about ethical concerns specific to letter data studies, and consider the rationale and process of carrying out mixed or multimethod studies.

2.8 Summary

This review has identified a wealth of strengths to using letters in research, including the creative and reflective opportunities it offers, benefits that stretch outside of the study such as the cathartic nature or writing letters, the use of pre-existing letters which may help lessen burden to participants, and the use of letters alongside a focus group to help enrich the data and support participants to engage in the group.

Although many strengths were identified, several challenges have also been encountered which would need to be considered when choosing to use letters as

data. Researchers will need to be mindful of the possibility of brief findings, inability to clarify the meaning of what has been said and paying attention to ethical issues specific to letter writing such as the proximity, roles, and responsibility of the researcher.

A table summarising the key strengths, challenges and recommendation has been included for ease of use.

Table 10

Key benefits, challenges and recommendations for use of letters as data in qualitative research.

Benefits	Challenges	Recommendations
• Reading a letter at the beginning of a focus group may help 'break the ice' and create fruitful discussion (Laughey et al., 2021). • Letters could be combined with other methods such as interviews or social media analysis to allow for rich understandings. • There is flexibility in choice of application of epistemological frameworks to letter data. • Many types of qualitative analysis can be applied to letters. • Pre-exiting letters are uninfluenced by the researcher (Perrot et al., 2017). • Naturalistic letters may capture the views of individuals less likely to engaged in surveys or interviews (Schmitz et al, 2021). • Letters may act to support better understanding in individuals' experiences or future actions (Duff, 2010).	• There is potential to evoke difficult memories with this method (Day et al., 2023) • Pre-existing letters may not be fully representative of views (Burry et al., 2023) • Letters written for interventions may be influenced by concerns about how it my impact care or who it is to be read by (Cahalane et al., 2013; Kilgore et al., 2019). • Participants may not follow instructions (Sools et al., 2015). • There is a possibility of brief findings (Brown et al., 2023). • There is no opportunity for researchers to check meanings or confirm ambiguities in letters (Perrot et al., 2017). • No chance to check that participants have followed the instructions (Sools et al., 2015) • Lengthy instructions may contribute to high dropout	• Pay attention to what is not said in the letters (Shmitz et al., 2021) • Ask participants to title their letter with a take home message to help the development of themes (Brown et al., 2023). • Consider how to protect the well-being of participants given that letters are written in a time and location to suit the participant, often not under the direct observation of the researcher (Day et al., 2023) • Correspondence approach may support checking ambiguities and quantity of data. • Offer a variety of ways for participants to write and send letters e.g handwritten, emailed, posted. • Consider that participants may want to keep their letter. • Consider how long participants may need to complete their letter.

• Letter writing may provide participants with more time for contemplation and reflection compared to other methods of data collection (Day et al., 2023). • More colourful results containing metaphor and poetry (Laughey et al., 2021) • Richer messages communicated, and a more engaging analysis process for researchers (Laughey et al., 2021). • Creative and novel dissemination opportunities (Furman & Shukraft, 2077: Day et al., 2023; Timmis et al., 2013). • Participants may find the letter writing process cathartic or experience and increased sense of wellbeing (Mawdsley & Willis, 2023; Day et al., 2023) • Participants may be more honest in letters than in other routes of data collection (Cahalane et al., 2013)	rates (Hänninen & Sools, 2022) • Participants' ability and willingness to articulate their experiences in writing will be influenced by their literacy levels, and as such accessibility should be considered (Cahalane et al., 2013). • Increased processing burden on researcher if sending and receiving letters in post.	

In order to best support future studies utilising letter writing, a checklist of decisions and reporting items has been developed and included (Table 11). This is intended as a template based upon the findings and recommendations identified in this review. It is hoped that this checklist will support both the current study and researchers using this method in future to make clear and justifiable decisions around study design and conduct.

Table 11

Checklist for conducting qualitative research utilising letters

Area	Questions	Yes/No/Partly
Research aims	**Can you clearly explain and justify the use of letters?** • How will using letters support your study aims?	
Source	**Will you utilise pre-existing letters or will you ask participants to write a letter for the study?** • What are the pros and cons of using pre-existing letters or letters written for the study in relation to your research area or question? • Are there letters that are already held in archives which you could analyse? • Are letters written as part of an intervention, treatment or procedure which you could analyse? • Would it be beneficial to ask participants to write a letter as part of a study?	
Additional data collection	**Do you plan to use any other data collection methods in the study, and how does this fit with letter data?** • Could you supplement the letter data with another form of data, and why? • How/at what stage of research/will you combine the different forms of data? • Would there be any benefits or limitations to a mixed/multimethod study utilising letters as one form of data? • What might letters provide that another form of data may not? How could this be supplemented?	
Population	**Have you considered whether letters will be acceptable and appropriate for your participants?** • How can you make the letter writing task accessible?	

	• Who may be excluded due to the methodology? • Who may be more likely to take part? • What benefits or limitations may letter-writing provide for the specific population?
Ethical issues	**Have you accounted for ethical issues that may be specific to letter writing?** • Will you provide your participants the option to have their letter sent back to them? Do you intend to return the original letter to the participant? • Have you considered an appropriate distress protocol? • Have you considered how to provide avenues of support knowing that the researcher may not be there when the letter is being written/completed? • Have you considered the researchers wellbeing in receiving the letters? • Have you considered the possible impact of writing on the participants?
Epistemological stance	**Have you thought about your epistemological stance?** • How does this relate to letter data and interplay with the type of analysis you may choose?
Analysis	**How will you analyse the data?** • Is the qualitative analysis you have chosen appropriate for letter data? • What is your rationale for choosing this kind of analysis? • What strengths or limitations may this approach to analysis bring with letter data? • Are you completing a mixed or multi method study using letters as one form of data? If so, how will you choose to analyse the differing forms of data? Will you combine them or keep them separate? Can you comment on any similarities or contradictory findings?

Format	• How will you collect your data? (e.g. handwritten, emailed, audio recorded, online platform). Can you say why? • Have you considered the practicalities around the format you have chosen? (e.g cost and time of printing, posting, stamps). • How long will you give participants to write their letter? How might this impact the data and retention of participants? • How long do you want the letters to be? Why?
Sample size / number of letters	**How many letters will you aim to collect?** • Will you ask participants to write one or more letters? • Have you thought about using the correspondence method whereby researchers and participants correspond by letter? What is the rationale or pros and cons for this? • How does the number of letters align with your aims and other methodological factors, such as data sufficiency, type of analysis or practical project constraints such as time frame?
Instructions / prompts	**What instructions will you provide to participants?** • What is the rationale for this? • Will you provide detailed or less detailed instructions? • Have you thought about the kind of data you are hoping to receive? • Have you thought about how the instructions you provide may impact the data you are collecting?
Dissemination	**How will you disseminate your findings?** • Have you considered how you could creatively share the results? • Could you disseminate a collective letter? • Have you decided where and with who you would like to disseminate findings for meaningful impact?

2.8.1 Strengths and limitations of the review.

Table 12 details strengths and limitations of the systematic methods review

Table 12

Strengths and limitations of the systematic methods review

Strengths	A strength of this review is that it has provided researchers with further guidance on how to best utilise letters in qualitative research. By developing a checklist as part of this process (Table 11), this review aims to support researchers to more clearly document decisions regarding the use of letters in future articles, and in doing this more broadly improve the quality of the body of research utilising letters as data. Furthermore, this aims to make letter writing a more accessible and reliable research method, allowing researchers to more easily build on previous work.
Limitations	Due to the commonality of the search terms such as 'qualitative' and 'methodology' needed to identify the methodological aspects required of this review, the search was kept broad using these terms, and then narrowed by using a 'Titles' filter. This allowed the search to capture relevant papers whilst also ensuring the total number of papers retrieved remained within the scope and timeframe of this review. However, narrowing the searches by 'Title,' has potential limitations. While filtering by 'Title' can

reduce the number of papers to screen, it may compromise the thoroughness of the review, for example important papers discussing key methodological advancements might be missed due to vague or non-method-focused titles. It was found that some titles of papers are not very descriptive of their content, as such these papers would not get picked up by the search and would only be found using a search that includes ‘Abstract’ or ‘Full Text’.

Therefore, a limitation of the review is that other articles exist in which letters were utilised that were not captured by the search. As an example, studies utilising letter writing and the correspondence methodology within prison settings during the response to COVID 19 to support the continuation of research at this time were not identified (Maycock & Dickson, 2021; Maycock, 2022). Unfortunately, they were not captured as the search terms used in the review were not detailed in the title of these articles. Instead, they were found by searching for ‘correspondence methodology’ without a ‘Title’ filter on Google Scholar, then hand searching the reference list of a paper identified in the search (Maycock & Dickson, 2021). This highlights a broader difficulty of completing any methods review, as even though that search utilised broad search terms and did not limit the search to ‘Title’, the papers were only found by hand searching reference lists.

As not all papers using letter methodology were captured by the search, the papers selected may not be representative of the wider body of research using letter methodology, therefore this may have introduced a level of bias to the review as the synthesis and findings were based on limited information.

A future review could remedy these limitations and consider building upon this initial broad review by narrowing the search in alternative ways to using a 'Title' filter. For example, looking for letter use within certain populations may make the search more specific, and this may allow a researcher to search without 'Title' filter, to find other relevant papers using letters. Researchers could also consider limiting the date range, which may allow them to also search within abstracts or full text.

Additionally, some databases allow searching within specific sections of papers (e.g., methodology or methods sections). If possible, researchers could include searches within these sections to find studies that might not reference their methods directly in the title but describe them in the body of the paper.

Finally, researchers could consider that methodological advancements might not always be published in traditional peer-reviewed journals but could be available in reports, conference proceedings, or dissertations. Including grey literature could help

	overcome the limitation of relying on formal titles of peer reviewed articles.

2.8.2 Conclusion.

The purpose of this methods review was to better understand the use of letters in qualitative research, and the strengths and challenges around this. Many details regarding the methodological decision making around letter use were not detailed in the sourced papers, which may be a results of restrictive publication wordcounts. Nonetheless these missing details have made it difficult to draw firm conclusions around some of the operationalisation and decision making of using letters. However, despite some articles reporting limited details, this review has begun the process of better understanding this method, providing an overview and foundation for the use of letters in qualitative research.

2.9 Rationale for current research

The systematic literature review has identified that utilising letters in qualitative research is feasible and has several strengths that are applicable to rationale for the current study. For example, that participants may be more honest in letters, and there is the possibility to recruit individuals who may not be likely to engage in more traditional data collection methods such as interviews. As noted in Chapter 1, given the challenges experience by individuals with T1DE in not feeling understood by professionals, they may be less inclined to take part in research where there is more potential to feel misunderstood. Therefore, the strengths identified by the review provide additional reasoning to those described in Chapter 1 to support the rationale that this method of data collection could be suitable for the T1DE community, due to

the increased anonymity and further proximity to the researcher when completing a letter compared to attending an interview or focus group. Individuals with T1DE may feel more able to engage in a letter writing task with less concern of being misunderstood, or judged, allowing them to engage more fully.

Previous glucose monitor research has explored user experience primarily regarding the *utility* of the device (Gleeson et al., 2019; Overend et al., 2019). Instead, this research is interested in the user's relationship to the device; we hope to understand how individuals connect to, or are involved with, the device. It is felt that a focus on the relationship to the device could provide insights that are of use to practitioners and service providers. Findings may indicate recommendations that could be implemented in clinical practice, inform training for staff, or help the development of support for patients. Furthermore, findings could help to inform service developments given the recent T1DE pathway developments and pilot sites. This research could also offer understandings that may help those with T1DE to feel less isolated in their experiences.

2.10 Aims and Research Question

Based on the literature examined in Chapter 1, and informed by the results from the systematic methods review, following on from the rationale outlined above, the aim for the current study is:

- To gain insight and understanding of the relationship that individuals with type 1 diabetes and experience of disordered eating have with their glucose monitors.

Therefore, this project aimed to answer the following question utilising letters as a data collection method:

> ***"What relationship do those who have type 1 diabetes and experience of disordered eating write about having with their glucose monitor?"***

The aim and research question has been purposefully kept broad to support initial exploration into the previously unresearched topic (Korstjens & Moser, 2017).

3. Method

3.1 Overview

This chapter details the methodological processes used in this study. In this chapter, a rationale for the chosen qualitative research design is explored. Following this, my epistemological position is revisited regarding the methodology. The ethical considerations made for this research and involvement of experts with lived experience will be detailed. Lastly, the procedure used to collect data and the analysis are outlined.

3.2 Design

This study adopted a qualitative approach. Qualitative approaches allow the researcher to collect detailed descriptive information about participants perspectives (Sofaer, 1999). As such, this was deemed the most appropriate approach to address the aim of the study, which was to gain a detailed understanding of the relationship individuals with T1DE have with their glucose monitor. Furthermore, an exploratory qualitative design is indicated when understanding of an experience has not previously been researched and therefore understanding is limited. In these instances, a qualitative design can help provide rich exploration of experiences (Fryer, 2022).

The qualitative design used involved participants writing letters addressed to their FGM/CGMs. Letters have been chosen for the strengths mentioned in the introduction and identified by the systematic review; notedly, the opportunity to collect rich data (Laughey et al., 2021), to collect data that is honest and in participants to own language (Duff 2011). It was also felt this method could be an

alternative and acceptable way to engage individuals with T1DE in the study, as discussed in Chapter 1 and Chapter 2. Additionally, letters were chosen as a standalone data set rather than combining them with an additional method of quantitative or qualitative data collection as the systematic review identified that using letters as a standalone data set was feasible and can provide rich data. It was felt that utilising letters as the only form of data would meet the study aims, as qualitative data is supportive of gaining understanding and insight.

3.2.1 Epistemological stance

As previously mentioned in Chapter 1, this study is situated within a critical realist framework, which posits that an external reality exists, but that our knowledge of reality is always shaped by our perspective (McEvoy and Richards, 2003). The systematic methods review did not identify previous studies utilising a critical realist stance with letter data however it was felt to be an appropriate stance; by adopting this perspective it was accepted that the letters exist independently to my observation of them, and while participants' letters accurately reflect their own understanding and relationship to their FGM/CGM, this represents only one of numerous interpretations of this reality (Silijander, 2011). Additionally, my interpretation of participants letters will be impacted by my contexts, thus, the data collection and results presented are not considered a 'true' representation of reality, but they may go some way to offer an insight into the reality of participants relationships to their FGM/CGM (Fletcher, 2017)

3.2.2 Choosing Reflexive Thematic Analysis

Qualitative approaches to analysis of the letters were compared and considered in relation to the research question and study aims, as summarised in Table 13. Reflexive thematic analysis (RTA) (Braun & Clarke, 2023) was deemed the most

appropriate approach as it best fit the with studies purpose and theoretical assumptions. This approach to analysis allows the researcher to make interpretations of patterns and meaning across the data set and develop a rich and coherent report (Braun & Clarke, 2006). Furthermore, this approach to data analysis can be used with a critical realist epistemological stance (Braun & Clarke, 2021), as the reflexive approach to Thematic analysis highlights and incorporates the researcher's active role in knowledge production and researcher subjectivity is acknowledged (Braun & Clarke, 2021). RTA accommodates inductive analysis; this is where analysis is primarily grounded in the data. In this approach to analysis, data are not coded to fit a pre-existing coding frame, but instead 'open-coded' in order to best represent meaning as communicated by the participants (Braun & Clarke, 2013). Analysing data inductively therefore felt most appropriate due to the lack of literature on the use of FGM/CGM in individuals with T1DE. I was not approaching the analysis with any pre-determined theories.

Data can be coded across semantic (surface, obvious) and latent levels (implicit, underlying) (Braun & Clarke, 2006). As such, any item of information could be double-coded in accordance with the semantic meaning communicated by the participant, and the latent meaning interpreted by myself. As such, I acknowledge that in RTA 'pure' inductive analysis is not possible, as I will inevitably bring my own worldview and perspective to the analysis.

Table 13

Considering other qualitative approaches to analysis.

Qualitative methodology	Description	Reason not chosen
Grounded Theory	• Inductive approach • Aims to develop theories grounded in real-world observations. • Used with various epistemological stances. (Charmaz & Thornberg, 2020)	• This study was not aiming to develop a theory or model from the data set.
Interpretative Phenomenological Analysis	• Detailed examination of an individual's personal lived experience and unique details of each case, with the aim of understanding the meanings participants attach to their experiences • Focuses on specific phenomenon in detailed exploration. • IPA is rooted in phenomenology. (Eatough & Smith, 2017).	• This approach was dismissed in favour of RTA, as RTA allows for broader research questions, and the hope of the research was to identify patterns across the letters for the exploration of the data to remain broad. • IPA is attached to a phenomenological epistemology, which was not in line with the critical realist approach used in this research. (Smith & Osborn, 2008)

Content Analysis	• Theoretically flexible • Can involve counting and measuring frequency of content. • Often uses deductive coding or coding frameworks. • Usually calculates inter-coder agreement. • More descriptive than interpretative. (Bengtsson, 2016)	• Exploratory nature of study required a deeper understanding of participants relationship to the device rather than a surface- level description and frequency of content. • Inter-coder agreement measures do not typically fit with a critical realist stance, as CR would not be working towards agreement or a single 'true' meaning inherent in the data. (O'Connor & Joffe, 2020)

3.2.3 Involvement of experts with lived experience.

Consultation was requested for the project from those with lived experience of type 1 diabetes alongside current or previous disordered eating. An advertisement was posted on social media platforms X (Twitter) and Instagram through the accounts associated with the study. Two individuals offered consultation to the project. They were informed that they could contribute as little or as much to the project as they were able to; areas where they may wish to be involved were presented to them at the beginning of their involvement (Table 14). Consultants were reimbursed for their time and emotional labour. Consultants were offered £10 per one hour of their time. This was capped at the value of £40 each, due to available funds for this project. Other possible benefits of being involved, outside of monetary reimbursement, were considered with consultants such as, learning more about a topic, connecting to other experiences through study results, or contributing towards positive change.

Due to the lived/living experience of consultants, it was important to consider their wellbeing whilst advising to the project. They were encouraged to let me know of any difficulties they may experience in relation to their involvement in the project or any ways their wellbeing could be supported.

As the research question had developed from a recommendation made by Wallace et al. (2022), indicating that it may be of use for future research to explore diabetes technology use with those who have disordered eating behaviours, experts by lived experience were not consulted about the population of interest and the overall research question, however, on learning of the research question they expressed that it felt an important area of research. Table 14 below shows the suggested opportunities for consultation in the project, and the outcome of consultation. Consultants were also asked for their suggestions for areas of consultation, but they did not generate other ideas that had not been thought of.

Table 14

Experts with lived experience involvement

Research stage	Tasks	Consultation outcome
Methodology	• Supporting development of letter writing task • Providing feedback on recruitment poster • Supporting recruitment	• Letter writing task felt acceptable and instructions would help people share how they actually feel. • The letter writing instructions were reviewed by one of the lived experience consultants involved in the project, who felt they were well worded and compassionate. • Comments were made that the sources of support were helpful as often support can be difficult to source.

		• Feedback was provided on posters that all questions that they may have had were answered on the poster. No changes were made to content of information. • Feedback was offered on language. It was recommended to change the phrase “type 1 diabetes and co-occurring disordered eating” to “type 1 diabetes and disordered eating” which was altered.
Analysis	• Reviewing the themes • Reviewing language	• Reflections on the language used in a subtheme named ‘reduces burden of diabetes’ were provided, highlighting the contradictory findings, leading to a revision of the theme name.
Write up	• Assisting with recommendations	• Suggestions were made that it would be helpful to share findings with clinicians, to help understand nuanced relationships to the device.
Dissemination	• Reviewing and suggesting methods for dissemination • Support with community dissemination	• Suggestions were made to disseminate to JDRF, Diabetes UK, the T1DE pilot sites, and a children and young persons T1DE working group. • Support with dissemination to conclude after submission.

3.3 Participants

3.3.1 Recruitment.

Recruitment took place outside of healthcare settings. This was due to the concern that recruiting within health services and may unintentionally exclude those participants we were hoping to recruit for the following reasons: T1DE is not always recognised by some healthcare professionals (Diabetes UK, 2024b), T1DE does not

have a diagnostic criterion, and there are only a small number of specialist T1DE organisations that could have been recruited through.

Furthermore, due to the underrepresentation of males and individuals from the global majority in eating disorder settings (Nwuba & Spinn, 2024), it was also felt that seeking participants through social media may help with widen access and include a more diverse and representative sample.

Participants were recruited using volunteer sampling (Alvi, 2016), through using advertisements on social media (Instagram, X, Facebook, Mumsnet) (See Appendix G), with a research account set up for the study, and via the Diabetes UK general message forum. Other diabetes and eating disorder organisations were contacted but were unable to support recruitment at the time due to their capacity. The type 1 diabetes research charity, JDRF, shared the research on their social media accounts. Consultants also shared the recruitment poster with their peer groups. Recruitment posters were shared several times on each platform across a period of 6 months.

3.3.2 Participant criteria.

Table 15 shows the inclusion criteria for the research. As there are no current diagnostic criteria for T1DE, and the current T1DE definition is not well defined, inclusion criteria were based on the proposed T1DE diagnostic criteria (RCPSYCH, 2022), including restriction of insulin and other compensatory behaviours, such as dieting or laxative use in aid of losing weight or remaining at a low weight (Table 15). By drawing on the RCPSYCH criteria published in 2022, this study adopts a narrower definition of T1DE than has been adopted by some in more recent times since the study was undertaken, which includes discrete diagnoses of other forms of disordered eating, like bulimia or anorexia under the classification of T1DE (JDRF,

2024). As such the criteria, for this study is more closely related to what may have previously be understood as ‘diabulimia,’ before it was termed T1DE.

As the NHS supports accessibility to diabetes technology, more recently providing many individuals living diabetes with free FGMs/CGM’s (Diabetes UK, 2024d), those living outside of the UK were excluded from this study. It was felt that experiences of using diabetes technology may be quite different out of the context of the UK, where diabetes technology may be less accessible due to costs and availability.

Table 15

Participant inclusion criteria

Inclusion criteria

• Living in the UK
• Aged 18 or over
• Living with type 1 diabetes
• Use a flash/continuous glucose monitor, and have done for at least 12 months
• Do NOT have to have been given a diagnosis of disordered eating but identify as currently or previously experiencing disordered eating/diabulimia. For the purposes of this study this was identified as any of the following:
  ○ regularly omitting insulin in aid of losing weight or remaining at a low body weight.
  ○ engaging in rigid dieting, binge eating, excessive exercise, laxative use in aid of losing weight or remaining at a low body weight.
  ○ intentionally keeping blood glucose high with the intention to keep weight low or lose weight.
• Provide informed consent

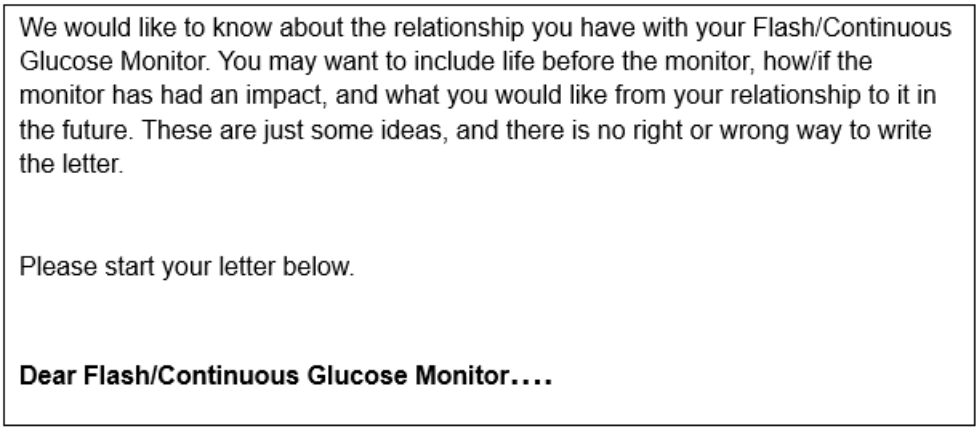
3.4 Data collection method

The data collection route was via letters written by participants. As the systematic methods review indicated it was feasible to conduct research whereby participants wrote and submitted a single letter, and that rich data could be gleaned from this approach, all participants were asked to write one letter. Additionally, it was felt that utilising a single letter, rather than a correspondence method (where letters are sent back and forth between researcher and participant), fit with the timespan of the project and aligned with the epistemological stance of critical realism, in that the letters would be less influenced by the potential responses of the researcher and may therefore remain closer to the subjective experience of participants. There was no upper- or lower-word limit to allow participants freedom in their writing (Day et al., 2023), but participants were encouraged to write enough so that we were able to gain a rich understanding of their experience. Participants were given the option for letters to be handwritten, digitally written or voice recorded to support preferences and accessibility in taking part in the study

Participants were asked to direct the letter to their FGM/CGM. The decision for participants to write *to* the FGM/CGM instead of *about* it was made as it was felt that by framing instructions relationally, participants may be more likely to write about their thoughts and feelings than if they had been asked to tell us about the device, where they may have focused more on the utility of the device. General instructions for the letter writing task were given, including instructions not to worry about spelling and grammar (See Appendix H). This was followed by the specific letter writing task. (Figure 5). Instructions were provided that were detailed enough to encourage participants to think about their relationship to the monitor over time, but also open enough to invite a range of imagined responses (Gross et al., 2023).

Figure 5

Letter writing prompt



Demographic information was collected simultaneously with the consent form; this included age, gender and ethnicity (See Appendix I). This information was collected to provide a richer context for understanding participants experiences, to identify if certain groups were underrepresented in the sample, and to support transparency in reporting who took part in the study and therefore who's voices were included. These factors are further considered in the discussion, Chapter 5.

There are no set sample size requirements for RTA research (Braun & Clarke, 2022); instead, researchers are encouraged to balance practical factors and theoretical/methodological priorities. There is scant research using single letters written by the participant specifically for the study to collect data, however a similar study collected 20 letters (Day et al., 2023). Additionally, the systematic methods review indicated that it could be anticipated that letter data may be information rich, which would generally require fewer data items (Braun & Clarke, 2022). Therefore, the project aimed to recruit between 15 – 20 participants, this number was chosen to satisfy the competing priorities at play regarding time, budget and methodological considerations. As such, it was felt that 15 – 20 letters should provide enough data to ensure new and rich understandings could be generated within the scope of the

project. Sixteen letters were received, ranging from 181 words to 2125 words (792 words average). The richness of the content of letters did not necessarily correlate with the length of the letters, in that, some of the shorter letters had an unexpected depth. Furthermore, across the data set there was a depth to the content of the letters that was deemed enough for the purpose of the study and allowed the research questions to be addressed. The concept of stopping recruitment at data saturation, defined as 'information redundancy' or the point at which no new themes or codes 'emerge' from data, is not adopted in this study. Low (2019, p. 131) argues that saturation defined as no new information 'is a logical fallacy, as there are always new theoretical insights to be made as long as data continues to be collected and analysed'. Furthermore, data saturation does not align well with assumptions and values of RTA, as for example, it cannot be known before analysis takes places what meaning may be generated through interpretation, and therefore data saturation cannot be wholly predicted ahead of this (Braun & Clarke, 2021).

3.5 Ethical Considerations

Ethical considerations are summarised in Table 16 blow.

Table 16

Ethical considerations

Ethical Approval	This study has been approved by the University of Hertfordshire's Health, Science, Engineering & Technology Ethics Committee protocol number, LMS/PGR/UH/05465 (See Appendix J). Two amendments to this permission were requested and approved during the project: Firstly, adding an additional question to the registration form to ask where participants had found out about the

	study, at the request of JDRF (See Appendix K), and secondly a request to remind participants twice instead of once, to write their letter if it had not yet been received by the researcher following their consent to participate (See Appendix L).
Informed Consent	A participant information sheet, containing important information about the study was included in the online registration platform. This included information about the study, the eligibility criteria, participants right to withdraw, information about the procedure, information about the potential benefits and risks of taking part, information about confidentiality and data protections, and plans for disseminating letters (See Appendix I). Participants had to read the information sheet and consent form (See Appendix I) and agree that they consented before they were able to fill out the screening questionnaire (See Appendix I).
Confidentiality & Data Protection	To ensure confidentiality participants were informed that their letter and data would be handled to maintain anonymity, in line with the University of Hertfordshire ethical committee guidelines and approval. This included saving letters separately to demographic information and using password-protected files, storing data on the secure UH one drive, and they were informed that any identifiable information disclosed in the letter would be omitted. Participants took part in writing letters in a place of their choosing, as such, privacy could not be guaranteed, but they were encouraged to complete the letter writing in private, as stated in the information sheet and instructions.

Right to Withdraw	Participants were informed that they could withdraw their letter from the research up until two weeks post submission. This time limit was imposed to allow participants time to consider their submission to the project but created a cut off for analysis to commence. Due to the nature of the analysis (RTA), letters would need to be analysed in relation to others, making it difficult to remove data later.
Participant Wellbeing	As this study was related to participants experiences of living with a chronic physical health condition and disordered eating behaviours, it was important to consider how participation may impact them. Although it was anticipated that the study should not cause distress, it may be that it evoked distress caused by their difficulties. This was important when considering that we would not know when participants would complete their letter, and as such we would be unable to provide a debrief or support at the time of completion. It felt important to send contacts for further support alongside the letter writing instructions (See Appendix M), prior to participants writing the letter. Participants were encouraged to contact the documented services (e.g., GP, diabetes services, Samaritans, diabetes UK support) should writing the letter bring about distress that they feel they need support to manage. Participants were informed that due to the professional code of conduct that I could not personally support individuals beyond the remit of the study, and instead they would need to contact someone on the list for further support. Once letters were received, participants were sent a standardised debrief, thanking them for taking part, explaining the rationale for the study, and reiterating the list of contacts for further support (See Appendix N). Although the systematic methods review identified that

	researchers have suggested the use of personalised acknowledgements of letters, this was not approved by the ethical committee for this study. The committee stated that it would not be possible to know what the process was like for the person completing the letter, and the letter received may not be the only draft that was made, that as such we would not necessarily be able to match a debrief to their experience accurately. Therefore, one standardised response was made to encompass receiving a variety of letters, to thank participants, acknowledge that the letter may have taken much time to write, and may have been an emotive experience. This point will be considered further in the discussion, Chapter 5. A distress protocol was devised (See Appendix O) in the event that participants contacted outside of expected communication raising concerns about disordered eating or diabetes management practices.
Researcher Wellbeing	When considering myself as the researcher, it was important to not share research adverts on my personal social media, and only use UH email address and postal address for correspondence and data collection.

3.6 Data collection process

Participants were asked to respond to the research advertisement on social media platforms via a link, or to email the researcher for the link. The link took them to Qualtrics, an online platform, to register their interest. The Qualtrics form included the information sheet, consent form, and an initial screening questionnaire (See Appendix I). As there is no formal diagnosis for T1DE,

participants were deemed eligible to take part in the study if they self-identified that they met the inclusion criteria, including the criteria for T1DE described in the study information sheet (See Appendix I; Table 15). Recruitment information encouraged individuals to take part without a formal diagnosis of disordered eating, but when they identified with the inclusion criteria specified. The answers provided to the screening questionnaire were checked to ensure that potential participants met all inclusion criteria before proceeding. If participants were deemed eligible for the study, they were sent the instructions to complete the research task. If they were not eligible to take part in the study, they were informed by email. Participants were asked if they would prefer to hand write, electronically write, or audio record letters. Letter writing instructions were emailed or posted alongside information about contacts for further support (See Appendix H).

Participants were given up to four weeks to write their letters. If a letter was not received from consenting participants, they were prompted once at the end of this time frame, and one further prompt was sent two weeks after this, if a letter was not received. They were informed that if we did not hear from them, it would be assumed they no longer wished to take part in the study and no further contact was made. Participants were informed they could send their letter until the end of the data collection for inclusion, which was April 5th, 2024.

Participants who chose to hand write and post their letter were provided with a stamped addressed envelope to return their letter. Participants were informed when their letter had been received. This correspondence included a debrief and contact details for support if required. They were asked if they would like to know the results of the study, whether they would like the be

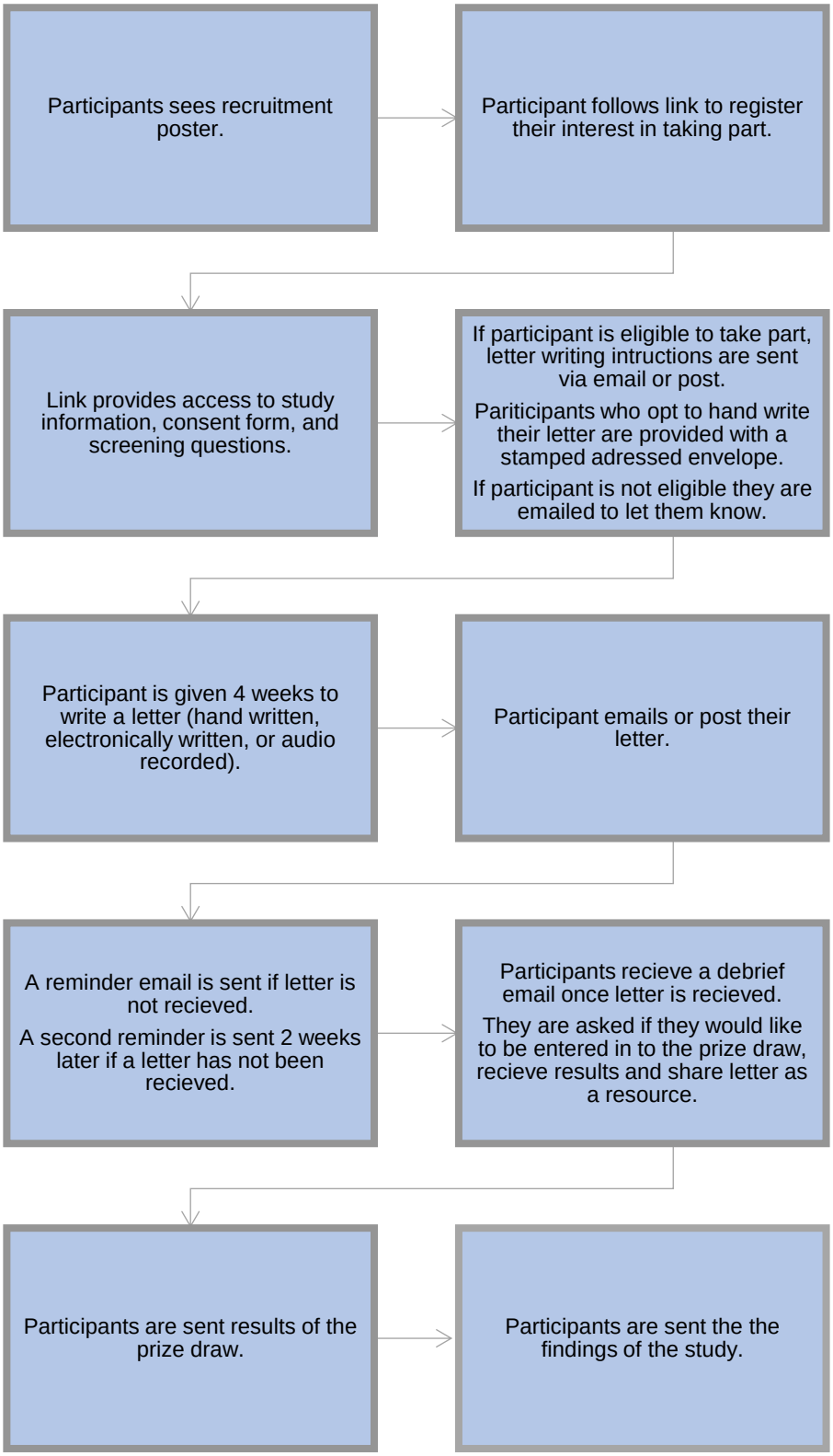
entered into a prize draw for taking part (first prize of £40 and second prize of £20 love 2 shop vouchers), and whether they would be happy for their letter to be shared (once anonymised), as a teaching tool.

Once data collection was completed, they would be emailed the results of the prize draw. It is important to note that participants could still enter the prize draw if they submitted a letter that they later withdrew.

All individuals who completed the study were assigned a number and entered into a random number generator. The winners were asked to sign a pay agreement for lay persons/participants before payment was made (See Appendix P). They were informed that the form will be stored on the secure UH one drive until completion of the project. The vouchers were sent via email. An overview of the sequence of events for participants can be found in Figure 6

Figure 6

Sequence of events for participants



3.7 Data analysis

Hand-written letters were to be transcribed into Word documents and combined with the other typed letters. The six phases of RTA described by Braun and Clarke (Braun et al., 2023) were drawn upon to undertake the analysis. A software programme was not used to undertake the analysis, instead opting to manually analyse the data. A combination of using Microsoft Word for data familiarisation, Microsoft Excel for initial coding, and printed codes and post it notes for the latter stages of developing codes and generating themes were used. I moved to the print outs and post-it notes to manually consider how codes started to connect as I found this allowed me more freedom of movement and I was better able to visualise the entire data set. Once I had developed and reviewed the themes, I moved back to Microsoft word to refine and define themes and write up the analysis. Each stage of analysis is described in detail in Table 17. Extracts from the coding process can be found in Appendix Q.

Table 17

Process of data analysis

Phases of Reflexive Thematic Analysis	**How I Engaged with the Phases**
Phase 1: Familiarisation with the Data	To familiarise myself with the data I read the letters multiple times; doing this allowed me to become intimately familiar with the content. I then began to annotate the letters to identify initial trends and points of interest in the letters.
Phase 2: Generating Initial Codes	Here, I went through all the letters and coded phrases. After reflective discussions with my supervisory team, I found that my initial coding had become too face value, in that it was often just

	mirroring the words used, instead of interpreting what had been shared. I noticed that I had chunked the data into too smaller phrases, as such some of the meaning was lost making it difficult to code. I revisited the data and recoded the data using larger phrases which allowed me to code the data at both a semantic and latent level. As the data was collected via letters, I was not able to confirm or clarify what participants were sharing. As a result, this sometimes left me feeling that some of the latent coding felt too removed from what may be being said. At these times I utilised my reflective diary to consider what I was bringing form my world view and what was reflected in the data. Sometimes this led to coding at the semantic level to stay closer to what was being described. The coding phase required a prolonged period of engagement with the data, with codes evolving with shifts in insight and multiple layers of reflection (Braun & Clarke, 2021).
Phase 3: Generating Themes	I utilised post it notes to group together codes that signified a broader pattern of meaning and experimented with different ways of grouping codes to highlight potential relationships. I repeated this process several times, resulting in the reshuffling of some groupings. During this process different themes were merged, discarded, or sorted into subthemes. The few codes that did not fit within any of the proposed themes were retained within a “miscellaneous” theme category in case they became relevant in later analysis.

Phase 4: Reviewing Potential Themes	Braun and Clarke (2012) outline five key questions to help review themes; drawing on these questions, I reviewed the themes in relation to their boundaries, whether they may indeed just be a code, whether there was enough meaningful data to support the theme, and whether the code was coherent. I continued to review the themes and subthemes until they told what I felt was a convincing story of the data and, whilst also addressing the research question. Therefore, at this stage some subthemes were dropped or merged as there was not enough meaningful data to support them.
Phase 5: Refining, Defining and Naming Themes	At this stage a definition was written for each theme to determine the story and core concepts. I reviewed the theme names; some had initially used quotations from the data, which I reassessed to capture the theme effectively. The consultants with lived experience of T1DE offered their reflections on the constructed themes and the language used. This was not in order to check the 'correctness of themes', as you may expect by 'member checking' data, but to instead enrich the construction of themes and feedback on the acceptability of the language used in the themes.
Phase 6: Writing Up	For this final phase quotations were chosen that represented the themes. Within this phase, there was consideration of the order in which the themes should be reported to connect them in a logical order, whilst also ensuring each theme was able to communicate

	their own narrative (Braun & Clarke, 2012). An analytic narrative and the quotations were woven together to produce the results. These results are presented in the next chapter, and later contextualised in relation to existing literature in the discussion section.

3.8 Quality, validity, self-reflexivity

The focus of RTA is not reliability or replicability, as in quantitative methods, but rather deep comprehension and interpretation of the dataset to gain a rich understanding of the topic of interest (Braun & Clarke, 2019). Quality practices such as triangulation, inter-coder agreement and participant validation to ensure reliability of the findings were not utilised as these practices are incoherent with RTA (Braun & Clarke, 2021) and critical realism (O'Connor & Joffe). With roots in measurement, the concepts of triangulation and member checking stem from positivist perspectives on rigour wherein multiple researchers or researchers and participants ideally converge on 'the truth' (Varpio et al., 2017). Instead, to support the validity of the study I engaged with reflexivity practices that allowed me to reflect on, document, and share biases that may shape the research (Table 18).

Reflexivity is an ongoing activity and should be carried out in all phases of the research project. Consequently, I examined my assumptions and biases with respect to the question being asked, the research process, and analytic process. Demonstrating transparency around reflexivity contributes to the validity of findings as it allows a reader to view the findings of the study within the context of these positionings. Reflexivity practices are detailed in Table 18.

Table 18

Self-reflexivity practices and reflections

Reflexivity practices	
Reflective journal	Throughout the project I kept a research journal recording queries, discussions with supervisors, thoughts after reading literature (See Appendix R). This enabled me to note and reflect assumptions I was making. For example, during analysis I noticed I was getting stuck on phrases in which participants were talking very explicitly around disordered eating behaviours, I often found these parts of the letters particularly emotive and hard to code. Reflecting on this in my research journal I noted that due to working within specialist eating disorder services for many years, I was getting caught on the content of what had been shared, these are things I would be curious about when working clinically, such as wondering whether participants were aware that what they were describing could be considered disordered eating, did they understand the risks of their behaviours, were they motivated for change? By taking a step back and noticing this, I was more able to view the statements from a research perspective and see these parts of the letters as sections of the wider data set, and in relation to the research question. This allowed me to interpret the meaning of what was being shared, rather than becoming overly focused on some of the details.
Writing letters	I wrote letters addressed to my thesis as an alternative form a reflexivity to my journal (See Appendix S & T). This helped me to consider the act of letter writing. I noticed that I was able to be freer and more creative with my thoughts, than when using a diary. I wrote 2 letters to my thesis. The first letter was written during recruitment (See Appendix S). Here I was surprised at how many participants had written that they had 'previously' experienced an eating disorder. I think this was due to my bias of working within specialist eating disorder settings where often there is narrative around the difficulty of recovery, as such I had anticipated that more people currently experiencing disordered eating may sign up. I also realised this was linked to a bias in thinking that the

	FGM/CGM may be detrimental to individuals with eating disorders, and as such they may be less likely to be recovered. Utilising the letter writing method, I was able to think about these biases and ensure that I paid attention to them during the analysis process to stay nearer to what had been described. This letter also encouraged me to think about the participant pool, and what this may mean for the findings e.g. may be a broad scope of experiences due to the timing of when an individual took part in the study and where they were in their relationship to recovery. The second letter was written after I had received and read a few letters (See Appendix T). I reflected on the content of the letters so far. I naively had not expected the lifesaving aspect of the device to be so prominent, and as such felt a sense of responsibility for the findings to not result in these devices no longer being offered to individuals with T1DE if the more negative aspects of the relationships to the device were shared in findings. This led to me to carefully consider how the findings were discussed and presented to ensure that potential solutions to difficulties could be discussed and recommended – in light of the devices being described if life changing despite their difficulties. To support my understand of FGM/CGM I trialled using one, I wrote a letter to the Freestyle Libre 2 before trialling it, this helped me reflect on my thoughts about it (See Appendix U).I noticed that for me this brought many concerns that were wider than the potential number to be display – such as not feeling confident in setting up the tech, whether it might hurt to put on, and whether this new information would impact my thinking about food. Doing this gave me some insight to the possible layers of challenges faced
Trial freestyle libre 2	I trialled the Freestyle libre 2 for two weeks and joined peers for reflective sessions before using, during, and after. This was in order to aid my understanding of the practical and emotional experiences of using a CGM, ad to reflect on my relationship to it, whilst keeping in mind I do not have T1DE, and as such would have a different experience to participants in the study. I felt this experience helped me understand the letters and more easily identify with what participants were writing about and the language used such as ‘staying in the green.’ I felt this experience went a small way towards grounding my understanding in the

	reality of the participants. At the same time, I was also conscious not to impose my experiences of using the CGM on to the data, so utilised these reflections when reviewing the themes to again ensure staying close to the data.
Supervisory meetings	Meetings with my supervisors during data analysis helped me to consider my biases. For example, having recently read that research and general understandings of eating disorders often portrayed an overly negative view on the ability to recover, I noticed myself wanting to portray positive change and hope within the data. I was encouraged to reflect on these assumptions, and to review the coded data to ensure I was reflecting what had been shared. Although many positive and life changing aspects of the relationship to FGM/CGM use were shared, I was conscious not to overstate this due to a want for this to be included.
EbE consultation	Two experts by experience helped inform the project, supporting with reflexivity around factors such as language use, details shared previously in this section (Table 11)

4. Results

4.1 Overview

This chapter first presents the Qualtrics data and demographic characteristics of participants to help situate the analysis within the context of the individuals who took part in the study. Then the qualitative analysis from the 16 letters received is presented. The aim of the analysis was to answer the research question outlined in Chapter 2: “What relationship do those who have type 1 diabetes and experience of disordered eating have with their glucose monitor?”. The analysis highlights the constructed themes related to the research question.

4.1.1 Qualtrics data and participant demographics.

The Qualtrics data indicated that 235 people clicked the link to access the registration form. Of these, 62 individuals completed the screening questionnaire. Of these 62 prospective participants: two entries were the same person, one person was not from the UK and therefore not eligible to participate, and one person later emailed after signing up to say they had changed their mind. Of the remaining 59, 16 participants completed and sent a letter, demographic information is shown in Table 19.

Table 19

Participant Demographics

Participant number	Age	Gender identity	Ethnicity	Years diagnosed with diabetes	FGM /CGM	Current OR previous experience of disordered eating	Letter format: Hand-written/ E-mail	Recruitment channel
1	31	Female	White British	11	Flash	Previous	Hand-written posted	No details as before amendment was made
2	38	Female	White British	20	Continuous	Previous	Word document emailed	No details as before amendment was made
3	35	Female	White British	4	Continuous	Current	Word document emailed	No details as before amendment was made
4	32	Male	White Scottish	29	Continuous	Previous	Word document emailed	No details as before amendment was made
5	54	Male	White	40	Flash	Current	Word document emailed	No details as before amendment was made
6	53	Female	White	31	Flash	Previous	Word document emailed	JDRF
7	59	Female	White British	20	Continuous	Current	Word document emailed	JDRF
8	44	Female	White	35	Continuous	Previous	Hand-written posted	JDRF
9	38	Female	White	3	Flash	Previous	Word document emailed	JDRF
10	26	Woman	White British	9	Continuous	Previous	Hand-written posted	JDRF
11	54	Male	White English	49.6	Continuous	Current	Word document emailed	JDRF
12	26	Female	White British	18	Flash	Current	Word document emailed	JDRF
13	40	Female	English	28	Continuous	Current	Word document emailed	Study Instagram account

14	22	Female	White British	9	Flash	Previous	Word document emailed	JDRF
15	24	Female	White British	16	Continuous	Current	Word document emailed	JDRF
16	27	Female	British	6	Flash	Previous	Word document emailed	JDRF

Eleven participants described themselves as a white female or a woman, accounting for the majority of participants. The ages of participants ranged between 22 and 59, with the time of living with a diagnosis of type 1 diabetes ranging from four years to around 54 years. Forty-four percent of participants used a FGM and 56% used a CGM. Out of the participants, 44% described themselves as currently experiencing disordered eating, and 56% described this as something they had previously experienced. Three out of 16 participants opted to handwrite the letter, 13 emailed a letter, and no participants opted to audio record their letter.

An amendment was made during the study to ask participants which recruitment channel they had signed up through. Five participants took part before the question was added to the form. Ten out of the 11 participants asked were recruited through the advert on JDRF social media, with one participant recruited through the advert on the Instagram platform linked to this study.

4.1.2 Themes.

Four main themes were constructed through RTA (Braun & Clarke,2023); ‘I Don’t Always Like or Want You...I NEED You... but I Wish I Didn't’, ‘Facing the Facts’, ‘You are Intertwined with Disordered Eating’, ‘You Communicate with Others’. Each theme comprises subthemes (Figure 7). The write up utilises quotes that were carefully considered to best portray the essence of a theme or subtheme, woven together with an analytic narrative (Braun & Clarke, 2006). Participant numbers allocated in Table 19 are attributed to quotes. The themes are not presented in order of significance or frequency, instead they are written in a logical and meaningful way to build a connected narrative of the data (Byrne, 2022). Some of the theme names have utilised language or phrasing from the data to capture attention and communicate an important aspect of the theme (Byrne, 2022). Additionally, some of the theme names

are written as if directed to the FGM/CGM, using the term “You” in reference to the device. The results will be synthesised and contextualised separately in the discussion section.

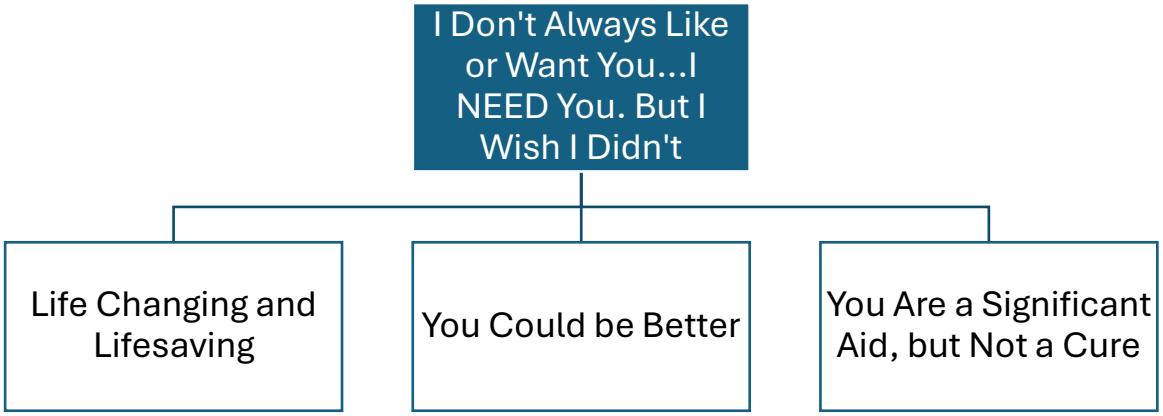
Figure 7

Themes and Subthemes

4.2 Theme 1: I Don’t Always Like or Want You...I NEED You... but I Wish I didn't

Figure 8

Theme 1: I Don’t Always Like or Want You...I NEED You... but I Wish I didn't



This theme begins to capture how the participants relationship to the FGM/CGM is complex and nuanced. The FGM/CGM is described to be supportive and life changing, and there is a sense of positivity and deep gratitude for the care provided by the device. Equally, participants describe elements of the relationship and the device that they do not like and would like to be improved. The relationship to the device is also described as a necessity, but a relationship they would rather not have to have.

4.2.1 Life Changing and Lifesaving.

This subtheme illustrates how participants feel that the FGM/CGM had changed their lives positively, often describing that it had allowed them to live a more ‘normal’ life and supported them to access activities they may not have felt able to without such as sports, and to also try new foods.

“I am very active. I have played semi-professional rugby in the past and train 6 days a week even now. Going to the gym is a very important part of my life. I have no idea how I managed playing rugby, cricket, going to gym etc when I wasn’t doing any testing!” (5)

"You have changed my life with diabetes in so many ways. You have given me confidence to be active, to try new foods, new activities and you have drastically improved my understanding of how my body works with diabetes. I am really grateful to you." (16)

Participants also shared that they see this device as 'lifesaving'. They spoke about this with a sense of thankfulness and an understanding the importance of the device for their safety in relation to manging their blood sugar levels.

"Continual scanning, magnificent, which stops me turning into a space cadet." (11)

"You will be saving my life for many days." (2)

There was a sense that participants put their trust in the relationship with the FGM/CGM, and for some this presented as though the device was 'looking out' for them.

"I know that you have saved me more than once, whether it be a miscalculation of insulin or that extra walk. You shouting at me telling me I am low – I can thank you again for that." (2)

Participants described that they were more able to manage their sugar levels when using a FGM/CGM, which in turn supported the management of short- or long-term diabetes complications such as hypoglycaemia, loss of eyesight and neuropathy.

"Since I have been diabetic the flash glucose monitoring system has been the biggest change and had most impact on controlling sugar levels. It has been superb." (5)

"My diabetes control is very good. I have no side effects eyes are clear, feet no problem. Nothing after over 40 years T1." (5)

There was a sense that for some participants the FGM/CGM was supportive in reducing the burden of diabetes; the practical and emotional aspects of diabetes management that can increase the mental load of those with diabetes.

"You really are a big help to me." (8)

Participants spoke more specifically of the practical and emotional benefits of no longer needing to finger-prick, they noted that FGM/CGM was less painful and less hassle.

"My fingers would like to say a big thank you. You have saved them from multiple daily stabbings. Non diabetics seem to think its painless but its not. Its not agonising but it sometimes can be really bloody sore and the scars come and my poor finger tips have been in a right old state over the years." (8)

"Part of the reason I didn't do any testing was due to the 'hassle' of blood testing. Finger pricks etc are just a major inconvenience. I think the reason I didn't test in the early days was because of this." (5)

Participants also shared how the FGM/CGM freed up their time due to the instant nature of it and ease of use.

"You show instant viewing, over 24 hrs, 1 week, 1 month. I don't need an Excel Spreadsheet anymore you are there, instant." (11)

The alleviation of time and lessening of the burden was also described by some participants when they were using the FGM/CGM alongside an insulin pump.

"I can't actually believe how much the work you all do together is freeing up time for me to live a more 'normal' life, albeit in the most abnormal way by some of the most absurd methods." (6)

With others looking to the future and the anticipated support an insulin pump may bring.

"Soon you will be talking to my other life saver – the pump and I am so excited for that day." (2)

4.2.2 You Could be Better.

Although participants spoke of many positive aspects of the device, this subtheme illustrates how participants wrote about limitations of the FGM/CGM and wishes they have for the device in the future.

Participants felt the device could be improved in terms of its design, naming the changes they held hopes for, such as the size of the device and other technological advancements such as a longer battery life.

"My wish for the future is that these devices, as incredible as they are, can be smaller – they are bulky on both my arm and leg/stomach and I am forever catching them." (15)

"When will you allow instant tracking and monitoring on a 'smart watch' to allow a glance rather than opening my phone & illuminating my bedroom to view in the middle of the night? When will 2 weeks battery life become 2 months, 2 years? When will it be instant, accurate, not an hour to wait when new, and a 5+ minute delay to reality? When will you shrink?" (11)

These limitations were also discussed in relation to wider systemic factors such as difficulties in access to new prescriptions when the sensor ceases to work prematurely.

"You do annoy me at times, a bit like a younger sibling – lost connectivity or when you fall off after 3 days and I am unable to get an additional prescription." (2)

These ideas are in contrast to the idea of a reduced mental load that the device is described to provide, noted in the previous subtheme "Life changing and Lifesaving".

4.2.3 You Are a Significant Aid, but Not a Cure.

This subtheme highlights how some participants described that the relationship to the device felt like something they would rather not have, an "arranged marriage" in which they had been "thrusted together", but in the absence of a cure for diabetes, it is a necessity. There was a feeling of a lack of choice in being in relationship with the device, and a sense of resentment both toward having diabetes and needing the device.

Although whilst recognising the positives, there appears to be a tension between the necessity of the FGM/CGM, and wishing it was not needed.

"I Love you always, even on the days I don't always like you or want you… I NEED you!"(13)

"There are so many positives about you and I am so grateful to have you in my life but I wish I didn't need you." (8)

"you are a significant help and aid, but still not a cure." (11)

An individual's relationship to the device seems to be linked to their relationship to their diagnosis of diabetes, which for some, there was a feeling of resentment. The device is described as a reminder of diabetes and a lack of freedom from the

condition. One participant naming the device as and ‘added weight,’ giving the sense that the device can actually be an additional burden to manage; again contrasting to the initial subtheme ‘Life changing and Lifesaving’

“You are a part of me that I fought so hard for, yet why do I have days where I don’t want you? I don’t want you on my body, I don’t want you telling me what my blood glucose levels are, and I don’t want you reminding me that I have this awful condition….Why? Because I am human. Because as thankful and grateful as I am to have you, living with Type 1 Diabetes is tough and sometimes we just need a minute to be free!” (13)

“For many others, I’m sure they’d welcome this technology with open arms - the alleviation of a burden, fantastic! - but those like me who had/have a contentious relationship with their diabetes, it can feel, at times, like an added weight that pulls me down.” (4)

This participant anticipated the FGM/CGM may change how they related to their diabetes, however the device seemingly did not alter how they felt towards their diabetes.

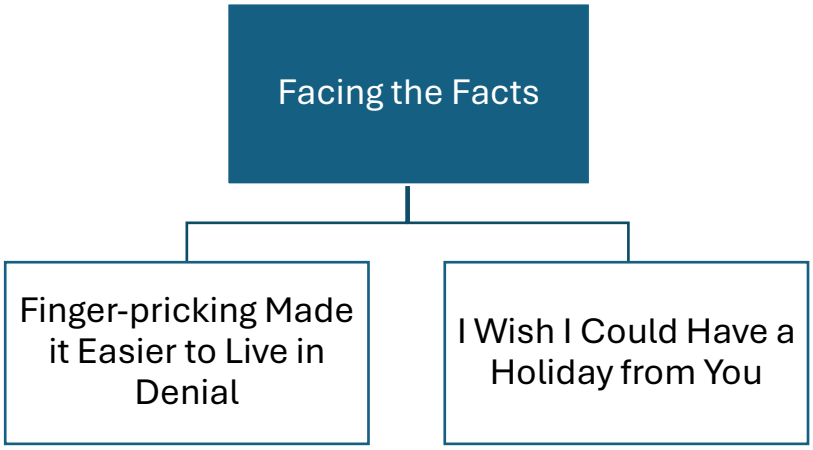
“I don’t think I thought you would solve all my problems, but I definitely hoped for a drastic turn around in how I felt towards diabetes. That may have been naïve.” (14)

Overall, this theme describes the necessity of the FGM/CGM, and that there are supportive aspects to being in a relationship with the device, however, across the letters this positivity was always coupled with difficulties, which are further demonstrated in the themes that follow.

4.3 Theme 2: Facing the Facts

Figure 9

Facing the Facts



This theme captures the idea that constant monitoring can feel 'overwhelming' and 'smothering'. This was illustrated through the idea that the continual access to blood glucose levels means individuals had to be more aware of their diabetes. There was a sense that participants want 'a break' from the device, and sometimes take steps to achieve this.

4.3.1 Finger-pricking Made it Easier to Live in Denial.

This subtheme illustrates how participants spoke of the device as an omnipresent being in their diabetes management and suggested that it was easier to 'live in denial' before having a FGM/CGM. Here there was a sense that the continual data impacted on their thoughts.

"You were supposed to make me feel safer and more in control, but instead, I felt smothered." (12)

"There is a downside – to be this 'good' at managing your sugar levels you have to pay a very heavy mental price. Diabetes is always there, on your arm. Test, test, test. What am I now, test, test, test…what am I now."(5)

One participant describing that the device left them with 'nowhere to hide.' It seems this increased knowledge of blood sugar levels comes with a feeling of 'being told

what to do' by the FGM/CGM, and in turn an increased pressure to manage the diabetes.

"With a CGM, I had nowhere to hide. By adopting this new method, I would have to reckon with my sugar levels on a far more regular basis. For many others, I'm sure they'd welcome this technology with open arms - the alleviation of a burden, fantastic! - but those like me who had/have a contentious relationship with their diabetes, it can feel, at times, like an added weight that pulls me down" (4)

"Diabetes now runs every aspect of my life because it's these on my are 'telling me'." (5)

Here the participant describes that they would like the device to 'become more like a friend again.' They described the 'numbers' as a 'huge red flag for how bad things are,' suggesting instead that the data provided from the device feels unfriendly or unkind. There is a feeling of powerlessness to change the 'numbers.'

"I hope that at some point, you can become more like a friend to me again. That I can start to use you as was intended, by using those numbers and graphs and charts as a tool to help drive me towards health, instead of something that acts as a huge red flag for how bad things are." (12)

Participants spoke of it being easier to ignore their diabetes before using a FGM/CGM. There was a sense that *'ignorance is bliss',* that being unaware of their blood glucose levels allowed them to be more carefree. Conversely, this lack of knowledge also meant they were vulnerable to risks, and participants also spoke of the harmful consequences, such as hypoglycaemia.

"It's hard to remember the finer details of how different my life was before then. I know that I didn't pay much attention to my glucose levels unless I was forced to by pregnancy or by hypos." (6)

"Finger pricking (or not finger pricking, to be more precise) made it far too easy to live in denial" (1)

Not only was diabetes easier to ignore, it seems that less attention could also be paid to disordered eating behaviours.

"If I didn't check my blood glucose levels I didn't have to eat and I was just injecting enough to convince everyone around me that life was going on as normal" (6)

"Maybe watching my sugars rise off the chart numbers would have made me realise I was doing damage. Maybe the alarms for high sugars would have been alarms as well to warn me I really was hurting myself. Maybe if I had a visual of my massively zig zagging blood sugars I would have had to face the facts that my out of control eating and insulin abuse was giving me no comfort what-so-ever." (8)

It seems that continually 'facing the facts' can feel relentless, and steps are taken to avoid seeing the 'numbers,' which is explored in the next subtheme.

4.3.2 I Wish I Could Have a Holiday from You.

This subtheme relates to how participants have responded to the constant monitoring and data provided from the device. Participants wrote that they would like to disengage from the FGM/CGM through 'having a break', some following this up by ignoring the device or turning the alarms off.

"Sometimes I pay a lot of attention to you, scanning and putting in information, and checking on that line to see where I am with my blood sugars. Other times I hear you screaming in the middle of the night and I can't help but ignore you." (9)

"I wish that at the same time as I have a holiday from work and all the other things I worry about in my life, I could also have a holiday from you. But with diabetes that's difficult." (16)

Although participants discussed 'wanting a holiday' from the device and wanting to turn it off, they also recognise that this might not be feasible due to the risks that unmonitored diabetes poses. This links to the subtheme 'You are a Significant Aid but Not a Cure' in that participants would rather not be in relationship with the device, but there is a feeling of little freedom in this choice.

One participant spoke about the time in between changing sensors, where a FGM/CGM can require a short warm-up period before it can provide accurate glucose readings, this can vary between 30 minutes to two hours. They described this time as the 'golden hour.'

"In fact, often my favourite time spent with you is when I've swapped arms and am waiting for you to be ready – I call this the golden hour, where I can have a little treat and it technically won't affect my blood sugars, because I can't see how they're behaving." (9)

The participant expressed that they hold a perception that their blood sugars would not be impacted by having a 'treat' because they were not confronted with the data which would alert them to the reality of the situation. There is a disconnect between what is actually happening in their body and what they are exposed to, and through that dissonance they are able to experience a moment of 'bliss.'

This participant also described turning the alarms off in aid of developing a better relationship to the device, food and their body. Suggesting, that it is hard to find a way in which individuals can be alerted and aware of high blood sugars, whilst also feeling satisfied with their relationship to food and their bodies.

"I've had to turn my high blood sugar alarms off to help our relationship, as well as my relationship with food, control and my body" (9)

This feeling of being in a no-win situation is further explored within the following theme.

4.4 Theme 3: You are Intertwined with Disordered Eating

Figure 10

Theme 3: You are Intertwined with Disordered Eating

This theme illustrates how the FGM/CGM is in relationship with disordered eating thoughts and behaviours, they can come as a pair, and are hard to separate. At times this relationship is described as conflictual; the FGM/CGM and disordered eating want different things. At other times the FGM/CGM and disordered eating appear to be working as a team, where the disordered eating takes the leading role.

Across the subthemes there was a feeling of being under pressure. This seemed to be located in different places, some was attributed to the device, other pressures were located within the self, such as striving for perfection and setting seemingly unreachable targets for themselves. In the context of diabetes, messages from wider discourses such as being a 'good diabetic' or being thin seen as the ideal, might contribute to the pressures individuals place upon themselves to reach a particular internalised ideal.

4.4.1 You are an Ally to Disordered Eating.

This subtheme highlights how some participants described the FGM/CGM as an ally to disordered eating. This highlighted a particularly concerning interplay that may be specific to those with T1DE. It is hypothesised that the increased access to blood sugar information may act as a support to disordered eating thoughts and behaviours such as insulin manipulation or binge eating. It seems that the FGM/CGM can even provide 'encouragement' as it acts as a safety net to risky behaviours; allowing individuals the opportunity to push their bodies and sugar levels to limits they would otherwise not be able to do without the device.

"I could've stopped using flash, but I knew I would never go back to finger pricks. You felt like the lesser of two evils, and if I was going to be messing around with insulin to lose weight, I'd rather do it with the safety net of easier access to blood sugar readings (even with no intention of doing anything with the inevitable bad numbers)." (12)

There is a sense that individuals can engage in these behaviours because of the trust they place in their relationship to the device, believing that the device will keep them safe, preventing a fatality.

"I binge eat. Some days I will eat xxx grams of carbs in an hour. Then test and inject insulin, binge again , test, inject insulin, keep eating, keep checking levels, keep injecting. Without the sensor I could not do this…I would be dead. I know it's down to me to not binge eat but if didn't have the monitor I simply wouldn't do it…as it would be certain death…yes I could do blood tests but it would need too many so I just wouldn't binge." (5)

One participant spoke of the CGM as though they were 'team members' working together towards a shared goal of avoiding weight gain.

"Once I received my first CGM (Libre), it almost became an ally against WEIGHT GAIN. Together, my CGM and I could control this. I quickly realised that I didn't care about time in range... all I cared about was keeping a flat line in the green zone and the only way to do that was to not eat." (7)

4.4.2 You are in Conflict with Disordered Eating.

In contrast to the previous subtheme, this subtheme illustrates the idea that the FGM/CGM is in conflict with disordered eating thoughts and behaviours. Participants spoke of a dissonance between what the device has told them and asked of them, and what their disordered eating wanted. There was a suggestion that individuals cannot get it 'right'. This manifested in opposing positions that should they work with their FGM/CGM, this is not in line with disordered eating, and if they follow their disordered eating, this is not in line with the support the device provides to manage their diabetes. The poses a dilemma, with a no-win situation.

"What you bring me in terms of mental peace and reassurance, you also force me to act in a way that erodes my body image more and more every day. It's not your fault. I know you're only here to keep me well. I just wish I could be well and not hate the way I look." (1)

For some the FGM/CGM became a representation of other forms of numbers or ways to be monitored, such as the scales or calorie counting.

"You feel so inextricably linked to my food intake – not in terms of blood sugar, but with calories – that's the difficult part that I don't know how to unpack." (9)

"I know you're there to help me, but when you show me my blood's figures and numbers it's like I'm looking at the scales again." (9)

Similarly to the ideas discussed in the subtheme 'I Want a Holiday from You' this participant described that they turned the alarms off. At this point, they were instead guided by their disordered eating. This highlights, how at times the disordered eating may win the conflict.

"I turned off the alarms letting me know I was out of range, because of course I was out of range. Half the time, I was in DKA. Eventually, I stopped looking at those numbers and purely focused on the numbers on the scale."(12)

Although in subtheme "Life changing and Lifesaving", participants describe feeling better cared for by linking their FGM/CGM to an insulin pump and excited about this, this also brought with it an opposing idea. For some it seems that using an insulin pump would be relinquishing the control of their insulin doses to the device, which appears daunting and something they did not feel ready for. It seems that if trust was placed in an insulin pump to support diabetes management, control on the disordered eating could not be retained, as they would not be able to refuse and manipulate insulin delivery. This further links with the idea of limits placed upon the freedom and choice in subthemes 'You Are a Significant Aid but Not a Cure' and 'I Wish I Could Have a Holiday from You.'

"I DO NOT want a pump as then I will lose control of being able to refuse insulin." (7)

4.4.3 Staying in the Green.

This subtheme illustrates a pressure described by participants to stay in the 'green zone.' This is in reference to the target glucose range displayed on the paired phone or device, which can be based on individual recommendations regarding factors such as duration of diabetes, lifestyle or patient preference. This sense of pressure

also appeared to be linked to dichotomous thinking around sugar levels and the green zone being ‘good’ and raised sugar levels as being ‘bad’. This subtheme encompasses how participants described setting themselves unsustainable targets and a sense of striving for perfection. This was demonstrated in relation to controlling sugar levels, but also changing eating behaviours that may impact these levels. Staying in the green seemed to be driven by different motivations. These included concerns of weight gain but also other fears such as long-term diabetes complications or wanting to be seen as ‘being good.’

“Nearly 10 years after it all started all the time I watch, scan & monitor hoping I can justify some chocolate/cake, or even if I don’t need to eat & my range stays in the green zone - stable. Those fluctuations above or below inspire fear of highs & the need to reduce my level back to green to minimise the risk of long-term complication or the joy of knowing I can eat, without requiring more insulin.” (11)

“I remember prior to you, I used the libre 2 sensor. I think initially this caused my anxiety to rise and I never felt good enough, you know? There was so much data there and I became fixated on being ‘good’, staying in the ‘green’ and reaching the 100% time in range target. I wasn’t very flexible or kind to myself back then” (3)

“I associate the yellow-zone-double-figures as weight gain, overeating or greed. In these times, I feel like a failure: frustrated, disappointed for allowing myself to eat or keep food down, and fed up with the hold this has on me.” (9)

Participants spoke of changing how and what they eat to remain in the green zone as the green zone conveyed a sense of feeling safe.

“Green is the safe zone. I’ve become used to foods that I wouldn’t normally eat – knowing I can have a bit of chicken, not need corrections, and not need to eat for several hours afterwards has become such a comfort. Which is mad, considering I used to be a strict vegan. Chicken, salad, nuts and coffee. And repeat.” (9)

“I became overfocused on staying in range meaning that I wasn’t eating when I was hungry to try and keep the ‘perfect numbers’.” (3)

There is a sense that being in the green zone becomes a place safer from judgment from eating disorder thoughts, or from feeling ‘attacked’ by the device. Participants

spoke to the idea that the device can at times adopt a powerful position such that they felt criticised by it.

"My biggest resentment was the hypers – any and every reading above 10mmols felt like criticism." (6)

"I miss certain foods, but I feel I can't allow myself to eat any of it and keep it down, or to have any more than a small mouthful. I miss pizza, cereal, bananas and all the delicious stuff. If I eat it, I'll spend the next few hours listening to you and what you tell me I've failed at, feeling powerless in how to bring myself back into my green zone." (9)

Here the participant personified the device as a bully, describing they feel worse when they are left alone together.

"It's so deeply personal, and sometimes feels like an attack. I think these feelings are worse when I'm on my own, or should I say when it's just me and you. (9)

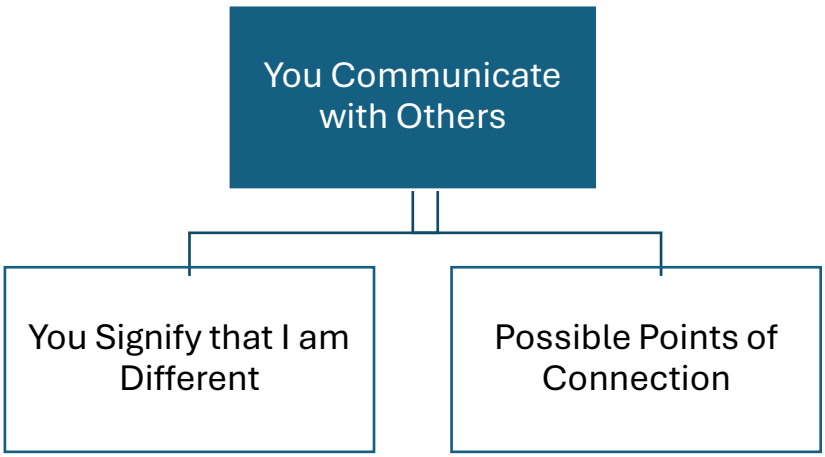
There is a feeling that in this relationship the device takes a leading role. This was expressed through the idea that participants become dependent on the FGM/CGM for direction and approval.

"The green zone is optimal; it tells me to keep doing what I am doing, which sometimes means not eating even if I'm hungry." (9)

4.5 Theme 4: You Communicate with Others

Figure 11

Theme 4: You Communicate with Others



This theme illustrates how the FGM/CGM is experienced as a means of communicating that an individual has diabetes through the visibility of the device. Therefore, the relationship extends beyond the individual and the device and invites others in. It seemed that when individuals *see* the FGM/CGM this brings them into the relationship, which has been experienced as both positive and negative.

4.5.1 You Signify that I am Different.

This subtheme relates to how the FGM/CGM is an indicator to others that an individual may have diabetes, and the associated feeling that the monitor distinguishes them as being 'different' to others. Participants spoke of the experiences of others which reflected a curiosity in others, but equally, that the monitor draws attention, resulting in some participants feeling like they need to keep it hidden.

One participant described hiding their device so that others would not 'spot a diabetic in the wild', giving the impression that the FGM/CGM signifies them as rare or a unlike others. This might also suggest a feeling of being watched or observed in some way, mirroring the constant observation on the device.

"I started putting sensors on my legs to make sure that no-one would ever spot the telltale sign of a diabetic in the wild, tied to technology." (12)

Here a participant described covering their device, this differed from the aforementioned reason, that might have reflected a sense of shame around the device. Instead, the associated burden in explaining its role to others was cited as the reason. They apologised to the device for covering it up, as though there is a sense of guilt in doing this.

"I was fascinated with you. Everyone was. People would stop me in public to ask what the round thing on the back of my arm was. A sticker? A nicotine patch? An electronic tag? I quickly grew tired of explaining type 1 diabetes over and over again, so to this day I keep you covered under long sleeves. I'm sorry about that. I'm not ashamed of you. It's just a lot of explaining to do sometimes." (1)

Some participants expressed their preference in keeping their diabetes hidden, which perhaps might relate to their own identity, sense of self and relationship to diabetes.

It seems that the experience of being identified as different can change over time. For example, one participant described how this intersects with their age, such that as they have gotten older this is a less salient idea in their mind. However, they also felt that an external factor of the addition of a pump, might further shift their experience. This highlights the unpredictability of the impact of new diabetes technology on identity

"Of course, I know you are the thing keeping my invisible illness from being completely invisible, but I think as I've got older I mind less about that and I think I would struggle a lot more if you were accompanied by your sister (the insulin pump)." (14)

Although other individuals seeing the device was often spoken about negatively, it was also stated that this could be an opportunity to build awareness about type 1 diabetes, demonstrated in the theme below.

4.5.2 Possible Points of Connection.

This subtheme captures the idea that the FGM/CGM is an opportunity for connection with others. It might represent a possible means to build a community or sense of belonging with others living with type 1 diabetes, and an opportunity for conversations and education to those outside of the community. Here the device is acting as a friend, making introductions. However, there can be missed opportunities to connect and understand, for example within a healthcare context. Whilst the FGM/CGM is a means of communicating data to healthcare professionals, this can also leave individuals feeling unseen due to missed opportunities to look beyond the small sensor to the whole person behind the numbers.

Here there was a feeling that without the sensor, there may be less opportunity to connect with others living with type 1 diabetes. These connections within the community seemed important as through this, there was a sense of a shared experience and comfort.

"There were four of us in our resort. Four type 1s, all visible thanks to our silly little sensors! In the summer I saw a barman wearing one and chased him around the pub just to show him mine! As you know, I'm not much of a people person, so that shows how compelled I feel to make myself known to other people like us." (1)

It seems the FGM/CGM can bring outsiders, such as friends, into the relationship with technology. There was a sense of pride in wearing the FGM/CGM and providing knowledge about the device to others.

I love it when my friends tell me they saw someone with a libre. It's one of the only easy ways to spot a type 1, and I love that other people know what they are because of me. (1)

A participant describes that the device provides a talking point that "normies" need, alluding to a lack of understanding of diabetes from those without the condition. Through these talking points, the FGM/CGM creates opportunities to bring more awareness about type 1 diabetes.

"But you also give me the talking point that the normies need. We need more awareness and better technology." (2)

Alongside friends and members of public, the device is also in relationship with professionals. There is a sense that professionals can focus on the data without exploration what might be required from an individual to produce those 'numbers', and therefore inadvertently praise the disordered thoughts and behaviours described in the theme "You are Intertwined with Disordered Eating."

Here, it seems there is missed opportunity for professionals to connect with an individual and explore the processes which underpin the numbers; in order to support in parallel both the management of diabetes and disordered eating.

"I cried in all the appointments I went to with health care professionals and no one really seemed to understand why. I'd get asked a lot 'why are you upset?' and comments would be made about how 'good' my numbers were." (3)

"Nobody really asked what I was doing to achieve those numbers" (3)

A participant spoke about a hoped-for alternative to this. They reflected on their feeling that, had they used a FGM/CGM sooner, their data could have signified their need for help. This demonstrates how the data hold the opportunity to communicate the need for support.

"Or maybe all this information could have been picked up from you by the hospital and someone could have seen how badly I was struggling and that I really really needed help and I wasn't the classic "bad" diabetic (God I hate that phrase) who just didn't care. I cared allright but I was trapped in a never ending battle" (8) .

"So maybe you couldn't have stopped me but maybe all that information you hold would have let someone else reach out to me and say "lets get this sorted." (8)

The conversations arising from data produced by FGM/CGMs could also be experienced as challenging, as if the device is sharing secrets held within the relationship between itself and the user.

"Looking through my graphs with a stranger as he asked what exactly I had eaten 2 Tuesdays ago and if I had insulined felt weirdly invasive and shameful." (10)

Participants also spoke of other incidences outside of FGM/CGM use where they felt they had been overlooked due to the numbers presented. In this particular instance, the participant was congratulated for losing weight, whilst 'under the grips' of disordered eating. Highlighting how wider perspectives about weight can enter the relationships held between individuals, monitoring devices and healthcare professionals.

"As I always did, I asked the nurse not to tell me my weight. She didn't, technically, but she did say "ooh well done you, you've lost half a stone!" I was so physically and mentally exhausted and wasting away again. But that one comment from the nurse made me feel justified. I didn't care when I went through to the consultant and he told me my Hb1ac was way too high. I was getting thin again!" (1)

Across this theme participants described positive and negative experiences of the increased visibility of their otherwise invisible condition.

4.6 Summary

This chapter has presented the four themes and associated subthemes that have been identified. The next chapter will provide a summary of the findings and consider how the findings relate to the current evidence base.

5. Discussion

5.1 Overview

This chapter begins by summarising the findings of this study in relation to the research question. Following this, the findings are contextualised within the existing literature, before outlining the implications for clinical practice and considerations for future research. A critical appraisal of the study is presented, including specific strengths and limitations of the study. Lastly, reflections on using the letter writing method and the overall research are detailed.

5.2 Summary of findings

This research set out to investigate the following question:

> ***"What relationship do those who have type 1 diabetes and experience of disordered eating write about having with their glucose monitor?"***

To summarise, participants appeared to have a dichotomous and nuanced relationship to their FGM/CGM. They expressed many positive factors about the device, with a sense of gratitude, and an awareness of what the FGM/CGM had brought them in terms of health and quality of life. However, this was paired with a variety of challenges in their relationship to the device, such as its constant and consuming nature. There also appeared to be an interplay, and at times conflict, between the support FGM/CGM devices provide in the management of diabetes and disordered thoughts and behaviours experienced that is specific to those with T1DE. At other times the data the device provides was described as supporting the engagement in disordered eating thoughts and behaviours. Overall, there was a sense that participants relationship to the device was also linked to their relationship

to type 1 diabetes, in that they expressed a hope for a cure and not wanting to need the device.

5.3 Relevance of the findings to the literature, implications and recommendations

In this section the four themes constructed through RTA (Braun & Clarke, 2023) will be considered in relation to existing literature and the resulting clinical implications. Whilst the themes constructed in this research correspond to the specific lived realities of the participants, they hold the possibility of improving the experiences of individuals with T1DE who use a FGM/CGM. The findings have implications for different levels of practice including professionals supporting individuals living with T1DE and healthcare policy (summarised in Table 20). Recommendations for future research are detailed in Table 21.

5.3.1 Theme 1: I Don’t Always Like or Want You...I NEED You... but I Wish I didn't.

This theme described a complex, nuanced and changeable relationship between individuals with T1DE have and their FGM/CGM. As demonstrated in previous research, this study found that participants had better control of glucose levels, improved access to activities and an increased sense of safety with less fear of unexpected hypoglycaemia (Dover et al., 2017; Mancini et al., 2018, Messer et al., 2017, Pickup et al., 2015). Similar to previous research, participants noted their hopes for improvements of the FGM/CGM, such as wanting a smaller device, a longer battery life, and for the FGM/CGM to have a stronger adhesion to the skin to prevent accidental removal. These findings corroborate with previous research undertaken with individuals with type 1 diabetes, where participants shared concerns

about the size and adhesive ability of the device (Messer et al., 2017). These findings provide technical product-specific feedback for pharmaceutical technology companies such as Abbott (Abbott Laboratories Ltd, 2024), Dexcom (Dexcom, 2024) and Medtronic (Medtronic, 2024), allowing future utility improvements.

There were conflicting results around the extent to which the FGM/CGM 'helped', with diabetes management as some participants considered this 'a big help', others suggested this felt like an added weight to manage. These contrasting findings for individuals with T1DE are consistent with existing research which suggests individuals with type 1 diabetes can find the devices both a help and a hindrance. More specifically, a sense of freedom and choice has previously been described (Gleeson, 2019) but equally, additional emotional burdens such as increased anxiety due to the constant nature of the device and concerns about accessing the technology have also been noted (Messer at al., 2017). These findings around the different perceived effects to diabetes burden as linked with the FGM/CGM, highlight the importance of strong clinical engagement with individuals using FGM/CGM. These findings suggest not to pursue a one-fits-all approach; members of multidisciplinary teams (MDTs) such as psychiatrists, diabetes nurses, dieticians, psychologists and other healthcare professionals should therefore take a person-centred approach.

In the present study participants expressed their preference to not have to use the FGM/CGM at all. It is hypothesised that participants' relationship to their FGM/CGM was similar to their relationship to their diabetes, with diabetes being described as an "awful condition", and wishes for a cure were shared. The way in which individuals relate to their diagnosis of diabetes may vary and can be changeable over time (Diabetes UK, 2024e). The experience of diagnosis has

previously been associated with a grieving process, in that individuals may experience feelings such as shock and anger, before moving towards a position of acceptance and adjustment for some (Nash, 2014). The findings within this theme indicated that depending on where an individual sits with these feelings could impact how they feel about the FGM/CGM. Therefore, it could be important for healthcare professionals to offer individuals the opportunity to discuss their feelings around their diabetes diagnosis, as this may provide a better understanding of how they relate to their FGM/CGM. Moreover, how far along the diagnosis process an individual is should also be considered.

5.3.2 Theme 2: Facing the Facts

Across the theme “Facing the Facts” there was a sense that the continual access to data and constant monitoring can feel overwhelming. This aligns with previous research which has found that individuals with type 1 diabetes can experience the device as overwhelming, attributed to a feeling that there is a lot of information to continuously manage (Kilvert & Fox, 2023; Messer et al., 2017; Wallace et a., 2023) This research corroborates these findings, identifying that this can also be the experience of individuals with T1DE.

To my knowledge this is the first study to identify how individuals may respond to the sense of overwhelm, constant monitoring and data provided. In response to these experiences, some individuals with T1DE sometimes ignored the device, turned it off, or disengaged from the information provided. Due to the necessity for individuals with type 1 diabetes to manage their blood sugar levels, an awareness of blood glucose data is unavoidable. As such it is imperative to consider ways in which individuals with T1DE can engage with the data with the least impact on their mental wellbeing. This could be supported therapeutically such as encouraging a less rigid

approach to diabetes management in individuals with T1DE in order to reduce associated negative affect of anxiety and guilt (Merwin 2015). It is hypothesised that if individuals with T1DE are supported to respond differently to FGM/CGM data, they may be less likely to disengage, and “have a holiday” from the device.

There is currently little tailored psychological provision for individuals with T1DE. However, a novel intervention, ‘STEADY’ (Safe management of people with Type 1 diabetes and Eating Disorders study), is being developed (Zaremba et al., 2022). Co-designed with individuals with T1DE and based on Cognitive Behavioural Therapy principles (CBT), the intervention is focussed on improving diabetes self-care whilst being embedded in a multidisciplinary healthcare approach. The core tenets of most CBT approaches involve encouraging individuals to notice their thoughts, feelings and behaviours in response to a situation (Kennerley & Westbrook, 2016). Incorporating the space and structure for individuals to explore their feelings, thoughts and relationship to their FGM/CGM would therefore be well suited to this newly developed provision, and may likely lead to better outcomes.

5.3.3 Theme 3: You are Intertwined with Disordered Eating.

This theme demonstrated novel findings regarding the intertwined nature of the FGM/CGM and disordered eating. It highlighted the process by which individuals with T1DE are able to use the increased access to blood sugar information to support disordered eating thoughts and behaviours such as insulin manipulation or binge eating. Additionally, the device can lead to the user experiencing internal conflict between their disordered eating thoughts and behaviours and what the is required for diabetic control according to device data. For example, blood glucose levels may indicate that insulin or food is required, which conflicts with their disordered eating thoughts or behaviours. There is no existing research which has

explored this unique relationship, and as such these are pertinent findings. However, when considering the broader understanding of diabetes and eating disorders, it has been suggested that there is a “symbiotic relationship between eating disorders and diabetes, characterized by a dynamic feedback loop wherein the presence of one condition can profoundly influence the course and outcomes of the other”. This results in a complex web of physiological, psychological, and behavioural interactions (Dziewa et al., 2023). The findings here contribute to this existing theory and suggest that the FGM/CGM can become part of this complex web. Specifically, through the increased access to blood glucose levels for diabetes management, participants were more able to engage in risky behaviours such as insulin manipulation, which could in turn influence the course of their disordered eating. This further highlights the importance of considering the presence of disordered eating in FGM/CGM users, as this may impact the trajectory of their diabetes management. These findings also affirm the concern that conventional treatments and services that address diabetes and disordered eating separately miss this interconnectedness. As such the results here support the existing call for individuals with T1DE to be supported by multidisciplinary teams within NHS settings that embrace an integrated approach to the care of individuals with T1DE and highlights the importance of the existing T1DE pilot sites. When considering this interconnectedness in relation to FGM/CGM it could be important for diabetes clinicians, dieticians and psychologists to jointly contribute to care and management plans. This joint working would help develop flexible, individual plans for those with T1DE to help them navigate the intricacies of managing their physical well-being in parallel to the recovery process from disordered eating. One such means of achieving this is for clinicians to draw on the “model of recovery from and resilience to disordered eating in type 1 diabetes”

(Harrison et al., 2021) described in Chapter 1. Here, weight and shape concerns can be managed through a more flexible diabetes plan, which could incorporate an understanding of an individual's relationship to their FGM/CGM.

The results indicated that there may be specific difficulties experienced by individuals with T1DE when using FGM/CGM. Policies and treatment guidelines should reflect this, for example acknowledging and addressing the conflict between disordered eating behaviours and the support provided by the FGM/CGM for stable diabetes management. However, the current guidelines provided by the National Institute for Health and Care Excellence (NICE) (NICE, 2024), who provide recommendations for the treatment and care of people by health professionals do not currently recognise T1DE as a clinical condition. As such, no specific guidance for the treatment of individuals with T1DE are suggested, with clinicians having to consult both the diabetes specific guidelines and eating disorder guidelines separately. Currently, the type 1 diabetes treatment guideline used in this way, notes "body image concerns" as the last factor for clinicians to consider when choosing whether to provide an individual with a CGM (NICE, 2022). Furthermore, there is no mention of FGM/CGM use in the existing guidelines for individuals with eating disorders (NICE, 2020). As such, little to no guidelines are provided to clinicians regarding the use of FGM/CGMs in individuals with T1DE. This is contrary to the findings in this theme, which highlights the essential need to include further guidance around offering and supporting the use of FGM/CGM in this group, due to the significance of the interplay between disordered eating and FGM/CGM use. The results go to further support the importance of developing specific T1DE treatment guidelines. However, in the absence of this, information relating to use of FGM/CGM

in individuals with T1DE should be included under both the diabetes and eating disorder specific guidance.

The findings within the subtheme “staying in the green” illustrated a pressure to remain in the target blood glucose range, which is displayed graphically on the paired device. This was driven by different motivations including concerns of weight gain, fears such as long-term diabetes complications, and wanting to be seen as ‘being good.’ Previous research has demonstrated the wish to ‘stay in range’, through rigid food routines e.g. eating the same food to keep blood glucose levels more predictable (Wallace et al., 2023). The authors noted that FGM/CGM data that does not fit with this rigid food routine may be received as criticism. This highlights a broad sense of pressure for individuals with type 1 diabetes to remain within range. However, in the current study, for individuals with T1DE there appeared to be a greater emphasis on how the green zone provided encouragement to engage in disordered eating behaviours, such as ‘not eating to remain in the green’. As a result, positive reinforcement from health care providers given to individuals that “stay in the green” without considering or discussing disordered eating behaviours may risk the health and wellbeing of individuals with T1DE. This strengthens the importance of avoiding the use of blood glucose data as a sole marker of diabetes stability in an individual with T1DE. Instead, blood glucose data should be interpreted against a wider picture, ensuring disordered eating thoughts and behaviours are discussed and considered with healthcare professionals.

Individuals with type 1 diabetes described similar feelings of critique in research examining the language used by healthcare professionals. This can be experienced as ‘critical, judgemental and blameful’ (Browne et al., 2014). Literature also indicates that people with diabetes can internalise stigmatising messages from

the media and from those around them, including health care providers. Specifically, the words people use impact how people with diabetes perceive themselves and how they experience living with and managing diabetes (Cooper et al., 2018). Therefore, in relation to their FGM/CGM, it could be that individuals with T1DE in this study experience the device as critical and judgemental due to stigmatising messages held about diabetes more widely in society and within healthcare settings.

Published guidance on the use of language in the care of people with diabetes suggests professionals should seek to be more empowering, encouraging and reassuring (Cooper et al., 2018). If individuals living with T1DE receive more encouraging messages from professionals, this may offset or alter how they interpret the messages from the device, such that they may be perceived as less critical. However, there is also a responsibility of device designers and manufacturers to protect users, particularly those with T1DE. The findings in this research suggest that outside of the routine FGM/CGM notifications and blood glucose data provided, the technology could do more to offer alternative messages. Previous research by Wallace et al. (2023) identified that it could be helpful for glucose monitors to offer the user a compassionate self-reflective message or a question. The findings in this study support the need for these previously identified recommendations. These changes could encourage the individual to pause, consider challenges they had overcome that day, or recognise how the data is making them feel. In doing so, this may support them to develop a more flexible relationship to the data and the FGM/CGM. For those who might find this feature helpful, integrating this as an optional feature could offset some of the negatively perceived messages.

Differing views were shared on the recent developments and increased access to insulin pumps and closed loop insulin pumps. Some individuals welcomed

this change and described ‘feeling excited’ to begin using their FGM/CGM in conjunction with an insulin pump. However, others did not yet feel ready to relinquish control of administering their insulin to a pump. As this study included both individuals who identified as “currently” or “previously” experiencing disordered eating, this finding may relate to the stages in the recovery from disordered eating. It could be anticipated that those currently experiencing disordered eating may be actively engaging in insulin manipulation in aid of weight loss. As such, the introduction of the pump may feel more threatening, due to the impact this may have on lack of control over disordered eating behaviours compared to in those who are no longer experiencing those concerns at the same frequency or intensity. These findings have implications for clinicians when introducing and suggesting a pump for individuals with T1DE, particularly in light of how the closed loop insulin pump technology is currently spoken of. With the technology described as “cutting edge” and will “revolutionise the life of people with type 1 diabetes” (NHS England, 2021), there may be assumptions made that this technology will be suitable for all individuals with type 1 diabetes. However, for individuals with T1DE it will be important for clinicians to consider differing experiences and views which appear to be linked to disordered eating thoughts and behaviours.

5.3.4 Theme 4: You Communicate with Others.

This theme highlighted that the FGM/CGM is a means of communicating to others that an individual has diabetes. This increased visibility was experienced both positively and negatively. Participants spoke of being identified as different to others, which aligns with previous research that has identified that FGM/CGM users experience heightened concern about others knowing they have diabetes, and the FGM/CGM can lead to a sense of being different. Contrary to this, other research

suggested that the absence of the need to finger-prick in public and having a reduced amount of equipment allowed some individuals with type 1 diabetes to more easily conceal their diabetes when using a FGM/CGM (Messer et al., 2017; Wallace et al., 2023). There are several campaigns and diabetes advocates which celebrate and promote the visibility of diabetes through CGM use. For example, Dexcom launched a campaign called #SeeDiabetes, aiming to encourage increased awareness and conversations around life with diabetes through portraits and stories of individuals wearing a CGM (Dexcom, 2023). As initiatives continue to support the understanding and awareness of diabetes, there is a hope that individuals may feel more comfortable for their diabetes to be visible.

In contrast to individuals being concerned about the increased visibility of their diabetes, some participants found the visibility of the device to be a means of connection to others with diabetes. Previous research has highlighted that peer support for individuals with type 1 diabetes can reduce the loneliness experienced by those living with type 1 diabetes (Nettleton et al., 2022). Both these findings highlight the importance of relationships with others with the condition. Therefore, individuals with T1DE could be encouraged to access peer support groups through organisations such as “Dream, Believe, Hope with diabetes”, an organisation dedicated to education, support, and advocacy for people with diabetes and eating disorders (Dream, Believe, Hope with diabetes, 2023). This is a recommendation that should be considered for inclusion within T1DE specific treatment guidelines and pathways.

The findings within the theme also highlighted that within a healthcare context there can be missed opportunities to connect and understand. Whilst the FGM/CGM is a means of communicating data to healthcare professionals, this can also leave

individuals feeling “reduced to a number”. This finding was also identified by Wallace et al. (2023), who noted that participants with type 1 diabetes described experiences of feeling judged solely by their blood glucose level or HbA1c (average level of blood glucose within two-to-three-month period). In this study the data was sometimes seen as a representation of who they were, regardless of their efforts or strengths elsewhere. Together, these findings indicate that improvements are needed in clinical interactions when reviewing the data from the FGM/CGM. This is of particular importance when working with individuals with T1DE due to the disordered eating behaviours described in this study which will contribute to these figures through several different processes. Existing guidance has suggested how clinicians can attempt to better understand a person holistically, for example through questions such as ‘Can we talk for a few minutes about your blood glucose levels, so I have a better idea of how things are going for you?’ (Cooper et al., 2018). However, more training should be offered to healthcare professionals working with individuals with diabetes on the use of language, and in particular how to adopt a curious and empathic stance around FGM/CGM data.

5.4 Summary of recommendations

Table 20

Recommendations relating to the care of individuals living with T1DE

For whom	Key recommendations
Diabetes technology companies	• Diabetes technology companies need to continue to develop the utility of the FGM/CGM. • The technology could offer alternative messages such as self-reflective messages or questions, to support the user to develop a different relationship to the data.
Healthcare services and professionals	• MDTs should offer person centred and case by case care, exploring with individuals their distinct relationship to their FGM/CGM, which may include both positive and negative aspects. • Psychological support should be provided for individuals with T1DE and should make space for individuals to explore their feelings around their diabetes diagnosis, as this may be linked to their relationship to their FGM/CGM. Psychological provision should also include structure to encourage individuals to share their thoughts and feelings about their FGM/CGM. These elements of psychological support could be included in the newly developing psychological provision. • Healthcare professionals should be curious about how individuals with T1DE respond to the constant monitoring of the device; paying attention to whether they are for example, turning off the device, ignoring the alerts or ignoring data provided.

	• Diabetes management plans should be developed including an understanding of an individual's relationship to their FGM/CGM. • Therapeutic support could include helping individuals with T1DE to respond differently to FGM/CGM data. If a less rigid approach to diabetes management can be offered this may support a reduction in negative affect, and therefore individuals with T1DE may be less likely to disengage with the FGM/CGM. • Individuals with T1DE should be supported by MDTs within NHS settings that embrace an integrated approach to care that considers diabetes and disordered eating simultaneously. • Joint working between diabetes clinicians, dieticians and psychologists would help support flexible plans for those with T1DE to help them navigate the intricacies of managing their physical well-being alongside supporting the recovery process from disordered eating. • Healthcare professionals should strive to use curious, empowering, encouraging and reassuring language in diabetes care more broadly, and around the use of FGM/CGM. • NHS healthcare professionals should receive training regarding the use of language in diabetes care, so that a curios and empathetic stance can be taken around FGM/CGM use. • Healthcare professionals should support conversations around the use of insulin pumps to understand individual perspectives and views on use when offering this to individuals with T1DE. These views may differ dependant on and individuals' stage of recovery from disordered eating.

	• Healthcare professionals should be made aware of the ways in which the increased access to blood sugar information provided by the FGM/CGM for individuals with T1DE may allow individuals to more easily engage with risky disordered eating behaviours such as insulin manipulation or other compensatory behaviours such as binge eating. The FGM/CGM can provide a feeling of a 'safety net' to engage in such behaviours. • Healthcare professionals should be made aware of the conflicting nature of the support provided by the diabetes technology, and what the disordered eating may require from the individual. As such there may be resistance to the diabetes technology. • Healthcare professionals should be made aware that individuals with T1DE may feel a pressure to 'stay within range' that is driven by concerns of weight gain, fears of long-term diabetes complications and wanting to be seen as 'being good.' • Healthcare professionals should remember that individuals with T1DE are more than a 'number,' and should attempt to understand individuals more holistically, and what is happening behind the 'numbers'. • Blood glucose data should not be used as a sole marker for diabetes stability or wellbeing, as individuals with T1DE may not be eating sufficiently to 'stay in the green' or could be engaging in other compensatory behaviours. Blood glucose data should be interpreted with a better understanding of the individual and with knowledge of disordered eating thoughts and behaviours.
Policy	• Specific T1DE guidelines should be developed and published by NICE. In the absence of this, current NICE guidelines for eating

	disorders and diabetes should be updated to include clear guidance for FGM/CGM use.
FGM/CGM users with T1DE	• Some individuals with T1DE may benefit from peer support, which may help to address feelings of being 'different'.

5.5 How the findings can be transferred to another population

Recently there has been encouragement to use FGM/CGM for individuals without diabetes, such as the Zoe study, which claims that using this technology supports long-term health and can help individuals reach a "healthy weight." (Zoe, 2024) These claims, and the use of FGM/CGM for individuals without diabetes more broadly, has received wide criticism. It has been suggested that there is no strong evidence that these devices help people without diabetes (Kar, 2024), and therefore the device has been marketed without any solid evidence. Within the context of cultural norms that value thinness, there is concern that an increased focus on this ideal may contribute to the development of disordered eating in individuals without diabetes (Kar, 2024). Furthermore, there is frustration and concern within the diabetes community that the trend among those without diabetes using FGM/CGMs takes resources away from individuals with diabetes and trivialises the seriousness of diabetes.

Whilst this study was limited to individuals with T1DE, findings may indicate that individuals without diabetes who use FGM/CGMs may experience similar difficulties as those in the current study. For example, as the focus of using the device for this group is on weight and health, individuals may experience similar concerns to those in this study regarding 'staying in the green' and an increased

responsibility to manage normal bodily functions. The findings from this research could therefore be used to contribute to the current discourse and emerging research around diabetes technology use in those without diabetes. In particular, it may aid understanding of the usefulness or necessity of this technology in individuals without diabetes, as well as highlighting some potential difficulties that may arise for this group.

5.6 Future Research

To my knowledge, this is the first study to explore the relationship individuals with T1DE have to their FGM/CGMs using qualitative methodology. As such, there are many avenues identified for future research to build on the findings of this study detailed in Table 21.

Table 21

Recommendations for future research

Research Area	Ideas for further research
Further exploration of themes	• Further research could look more closely at some of the themes that have been constructed here. It would be important to explore further the themes which are more specific to the experience of T1DE, such as subthemes "You are an Ally to Disordered Eating" and "You are in Conflict with Disordered Eating." This would help get a more in depth understanding of the interplay of diabetes and disordered eating, and the impact of the FGM/CGM for individuals with T1DE. Research could focus more specifically how this interplay may contribute to the development of disordered eating behaviours.
Research with other populations	• Application of the same research question to novel populations is also warranted. In light of the development of the clinical criteria for T1DE, it

	could be of use to distinguish specific populations of individuals with type 1 diabetes and disordered eating, such as those with diagnosed eating disorders (e.g., Anorexia Nervosa, or Bulimia Nervosa), or those within specialist eating disorder services, as differing relationships to the device may exist. For example, in the theme 'You are Intertwined with Disordered Eating' one participant noted using the CGM to enable binge eating, these behaviours may be significant in those with a presentation like Bulimia, and as such these differences may warrant exploration. • A similar methodological approach to that used in this study could also be adopted to help explore relationships to healthcare services and staff: Letters could be written to diabetes nurses or other clinicians, similar to the blog that inspired this study, to better understand the difficulties experienced for those with T1DE in healthcare settings, and the multi-disciplinary nature of the care.
Secondary analysis on letter data	• As the relationship to FGM/CGM for individuals with T1DE had not been explored before, the approach to this initial research was broad, including a wide research question and RTA (Braun & Clarke, 2023) to allow patterns across the data to be identified. This has allowed a greater understanding of the complexities, nuances and breadth of the relationship to the FMG/CGM. However, as ethical permission was granted to use the letter data in subsequent studies, it would be of benefit for future studies to analyse the data utilising secondary form of qualitative analysis. Both discourse and narrative analysis could lend itself well further understand the data (Earthy & Cronin, 2008; Trappes-Lomax, 2004). Discourse analysis would allow a researcher to more readily explore the relationship between language, power and social context (Trappes-Lomax, 2004). Alternatively, using a narrative analysis could allow the researcher to examine how the stories are told by examining the structure and the content of the letters (Earthy & Cronin, 2008).

5.7 Reflections on the use of letters

As in the systematic methods review, I have shared my reflections on using letter writing in this study in relation to the ‘benefits, challenges and recommendations.’ I have shared these in the form of a letter Figure 12 (overleaf).

Figure 12

A reflective letter on using letter writing as data collection method

Dear researchers,

I am writing to inform you about my reflections on utilising letter writing as the data collection method for this project. I do so in the hope that, if you are planning to use this method in future, these reflections are helpful and may support you in your research project.

I noticed that some participants in this study described letter writing as a cathartic and therapeutic process. In line with the findings of the literature review, these reflections indicate that there can be positive effects of letter writing that may extend outside of the study (Mawdsley & Willis, 2023).

As a researcher, it was incredibly engaging to receive letters in the post, creating a sense of excitement around reading a participant's reflections. There was a sense that some of the letters had been written with a lot of care and attention, which made me appreciate the participants time and the value in their sharing's. As a result, I wanted to ensure that I too took time and care to represent what had been shared. This, I believe, supported my engagement with the project and the analysis process.

The systematic methods review identified that letter data can be rich (Laughey et al., 2021), I also felt the letter data in this study was rich in quality; containing detail, emotion and metaphor, which allowed the analysis to capture the depth and complexity of participants relationships to the FGM/CGM.

Although there seemed to be numerous benefits to using letters for both me and the participants, there were also several challenges that it is important to consider. I found that when undertaking data analysis, there were some aspects of the letters where I would have liked to further explore with the participant to get more clarity on the meaning of what had been shared. As noted in systematic methods review, the use of letters does not always afford the ability to gain a deeper understanding, and care should be taken to not misinterpret meaning.

Although participants were given the option of writing hand-written letters, emailing electronically written letters, or audio recording their letters, most participants opted for electronic-written emailed letters. There may be many factors influencing this choice, such as convenience or handwriting ability. Whilst it is important to provide participants with options, emails were notably preferred by participants in this study. As such, researchers may want to consider this when designing a study as letters sent by email may be a more attractive option.

Finally, you should carefully consider how you will communicate with participants on receiving letters. On some occasions, the standardised debrief and avenues of support document did not feel sufficient for a response. For example, when participants wanted to check if their letter was what we were hoping for, or for example when a zine had been sent alongside the letter, it felt important to acknowledge this. This is similar to what one may do at the end of an interview or focus group. I think there would also have been some value in being able to respond more personally to what had been shared in the letters, particularly when they were full of emotion, or challenges experienced. I wondered what it may have felt like to write and send a letter like that and to receive little acknowledgment of the story shared. This would be something for you to consider at the stage of design and ethical approval, as this could provide more flexibility in how to respond. A more personal approach in response is indicated by Harris (2002), who suggest that it is important to acknowledge that letter writing can be an emotional experience and that the researcher should demonstrate care and empathy towards participants. As such they suggest that researcher could acknowledge what has been shared and include the impact the letter had on them, and the study overall.

I hope that these reflections will support you and inspire you to use letter writing as a data collection method in your study,

Yours Sincerely

Emily

5.8 Critical Analysis

5.8.1 Critical Appraisal.

A full quality appraisal is presented using the CASP (Critical Appraisal Skills Programme, 2024), followed by more specific strengths and limitations of the study.

Table 22

CASP Critical Appraisal of current study

CASP criteria for quality	Y = Yes N = No ? = Can't tell	Evidence
1) Was there a clear statement of the aims of the research?	Y	There was a clear goal. Reasoning for why the research would be important and relevant were identified and supported by the literature evidence around T1DE.
2) Is qualitative methodology appropriate?	Y	The research sought to understand the subjective experience of participants in rich detail. The Qualitative methods used supported the production of rich data, which is important in this context where there is limited evidence.
3) Was the research design appropriate to address the aims of the research?	Y	The design was appropriate: it was discussed how design was decided upon considering the benefits of qualitative research, the use of letters, and the pros and cons of using reflexive thematic analysis.
4) Was the recruitment strategy appropriate to the aims of the research?	Y	The paper explains how the participants were selected, providing discussion around where to recruit e.g. outside of clinical settings to increase accessibility. Considerations were noted as to why some people may not have taken part.
5) Was the data collected in a way that addressed the research issue?	Y	Using letters provided rich and nuanced data. How data was collected was described, the methods were justified and explicit. The form of data was clear. Saturation was discussed, but not adopted as it does not align with RTA.
6) Has the relationship between the researcher and participants been adequately considered?	Y	A number of methods of reflexivity were undertaken and noted to consider the author's relationship to the participants and the research topic.
7) Have ethical issues been taken into consideration?	Y	Sufficient details of how the research was explained to participants were provided, careful consideration was given to ethical issues

		specific to letter writing such as the proximity to the research on completion of letters and the need for signposted support beforehand. Additionally, The University of Hertfordshire ethical approval was clearly stated.
8) Was the data analysis sufficiently rigorous?	Y	An in depth analysis process is provided. The appendices transparently demonstrate how the themes were derived, with sufficient data is presented to support the findings. Some contradictory findings are noted, and I examined my own role and potential bias during analysis, the reflections of which were shared.
9) Is there a clear statement of findings?	Y	There is an explicit statement of findings, including discussion of contradictions. As discussed in the Chapter 3. Method section, triangulation, respondent validation or more than one analyst were not used in relation to credibility of findings as this does not align with RTA (Braun & Clarke, 2021). Instead, reflection on biases and process were shared. The findings are discussed in relation to the original research question, and considered in relation to existing literature
10) How valuable is the research?	The contribution of the research to existing knowledge is discussed, and new areas of research have been identified. A discussion on how the findings may be transferred to other populations is also included.	

5.8.2 Strengths.

One strength of this study is that it is the first study to qualitatively explore the relationships that individuals with type 1 diabetes and experience of disordered eating have with their FGM/CGM. Therefore, this study makes an important contribution to the field, providing rich and nuanced understandings.

An additional strength is that the data collection method will allow dissemination of findings to relevant services and clinicians in a few ways. Fourteen participants agreed for their full letter to be shared (once fully anonymised). These 14 letters can be shared as a pack to allow a reader to gain a full and immersive understanding of participant responses. This has provided the opportunity to

disseminate the findings in a novel and accessible way. A composite letter has also been developed; this is an amalgamation of the letters submitted which has attempted to convey the participant voices. We hope that it has remained close enough to the letters shared such that it can convey the emotions and meanings shared in an alternative way to reading the constructed themes. This composite letter can be accessed by relevant services and clinicians. It can also be shared with the T1DE community in the hope that it could connect individuals to other experiences, which may allow them to feel less isolated in theirs. This may also have the additional benefit of setting some expectations around the use of FGM/CGM, both for new and current users.

5.8.3 Limitations.

Most participants for this research were recruited via volunteer sampling from JDRF social media, which is likely to have shaped the sample recruited to the study. It is likely that those who took active steps to participating may have had specific experiences that may have motivated them to take part. With the JDRF aims in mind, (to help people live better with type 1 diabetes and find a cure for type 1 diabetes) (JDRF, 2024), participants recruited from here were likely already aware of a wider community of research and support. Therefore, they may have held different experiences to individuals who are not aware of the JDRF charity. As a result, their views may not be representative of wider experiences. We were also unable to promote research through any eating disorder (ED) charities or forums, due to their limited capacity to support research projects. In turn, it is possible that people presenting in ED communities may offer differing perspectives or experiences.

Although attempts were made to recruit a more diverse sample through advertising outside of clinical health settings and via social media, white British

females represented the majority of the sample. It is possible that a more diverse sample may have generated different results. More specifically, it would be important to hear from individuals from the global majority and those who do not identify as female. Current literature suggests that this was not a limitation unique to this study, as it is known that both men and individuals from the global majority are underrepresented in eating disorder services (Nwuba & Spinn, 2024). This is thought to be due to factors such as healthcare practitioners and community members lacking awareness that eating disorders can affect people from all ethnic backgrounds, as well as diagnostic biases and systemic barriers. It is possible that men and individuals from the global majority did not feel able to come forward due to previous experiences in seeking support or not identifying with the research. Alternatively, the sample may have been impacted by my identity as a white British researcher; it is thought that a feeling of 'sameness' can contribute to a feeling of trust, possibly increasing my ability to gain access to white British females (Bhopal, 2001). More efforts could be made in the future to recruit a more diverse sample through specifying particular demographic factors as part of the study or inclusion criteria. Alternatively, this could be more carefully considered by utilising participatory action research (PAR) (Baum et al., 2006). PAR is a collaborative research approach that involves all stakeholders in the research process, including those who are traditionally considered research subjects. In doing so, it aims to democratise knowledge production and empower participants. The trust that can be built between researchers and participants with this approach may encourage and support individuals to take part (Baum et al., 2006).

A further limitation is that there was a large drop out of participants, from the initial number who signed up, to those who went on to complete a letter. Difficulties in

non-retention are observed in studies utilising other data collection methods such as online questionnaires (Hoerger, 2010) and interviews (Skea et al., 2019), so may not be specific to the letter writing methodology. However, it is important to keep in mind that those remaining in the study may differ from those who signed up, but did not complete a letter, which may indicate some bias in the study results. In future, the retention of participants could be supported in a few ways. It may be helpful to lessen the burden on participants by utilising a web platform to streamline the process of signing up and submitting the letter through one platform, rather than having to download files, save and reply via email. A further way to support retention is the ability to pay participants at study completion, as a token of appreciation and gratitude (Pandya & Desai, 2013). Finally, something that could be tried, although not observed in any of the studies in the systematic method review utilising letter writing, could be to organise a time and date for the participant to write their letter, like the process of attending a study interview. This may help participants remember, or commit to, the letter writing activity. However, it would be important to consider what might be lost in doing this, such as the length of time participants are given to write a letter or flexibility in when to do it.

5.9 Final reflections

Upon writing up this research and thoroughly reviewing the literature, I have become aware of the body of research supporting the understating of diabetes, eating disorders, and more recently a small amount of research jointly for T1DE. With all this knowledge, it seems that something is missing; there is a barrier to joining up all the pieces of this complicated puzzle. I am left thinking about the parliamentary enquiry and the request for more funding. It seems this is a vital part of the existing

picture, and in order to offer improved and consistent support for individuals living with T1DE, more funding is needed to action what is already known. For example, some key areas that could be improved with sufficient funding are the continuation and expansion of the T1DE pilot sites, updating the NICE guidelines to improve treatment pathways, and improving education and training for healthcare staff on currently knowledge of T1DE.

On reflection, I could not have anticipated the journey and new understandings I would receive by embarking on this research. I now have an increased understanding of the daily challenges faced by individuals living with type 1 diabetes and those with T1DE, for which I am grateful. I hope to continue to develop these understandings and transfer them to clinical practice as a psychologist, allowing me to consider system level change and the psychological support for individuals with T1DE.

6. Conclusion

This thesis has provided a review of the literature utilising letter data in qualitative research and furthered understanding of how individuals living with type 1 diabetes and experience of disordered eating relate to their FGM/CGM. The findings indicated that individuals with T1DE can have a complex and nuanced relationship with their FGM/CGM, with both positive and negative aspects of the relationship being reported. The findings have further highlighted the importance of integrated care for individuals with T1DE.

This thesis provided a novel contribution to the growing research pool in the field of T1DE, with a unique focus on diabetes technology. As diabetes technology and services continue to advance, the findings from this research should be kept in

mind, actioned, and built upon to ensure individuals with T1DE are sufficiently cared for.

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Appendices

Appendix A

Search planning tool

Search Planning Form

Question : How are letters used in qualitative research

Identify the main concepts of the question (use as many as you need)

Concept 1	**Concept 2**	**Concept 3**
Qualitative	Letters	

List alternatives keywords, terms and phrases below

Concept 1	**Concept 2**	**Concept 3**
OR method	OR letter writing	
OR data collection method	OR letter-writing	
OR methodology	OR correspondence	
OR qualitative	OR letters	
	OR letter	OR
	OR narrative	

AND AND

Step 1: Use OR to combine ALTERNATIVE search terms together.

Step 2: Use AND to combine different concepts together.

Appendix B

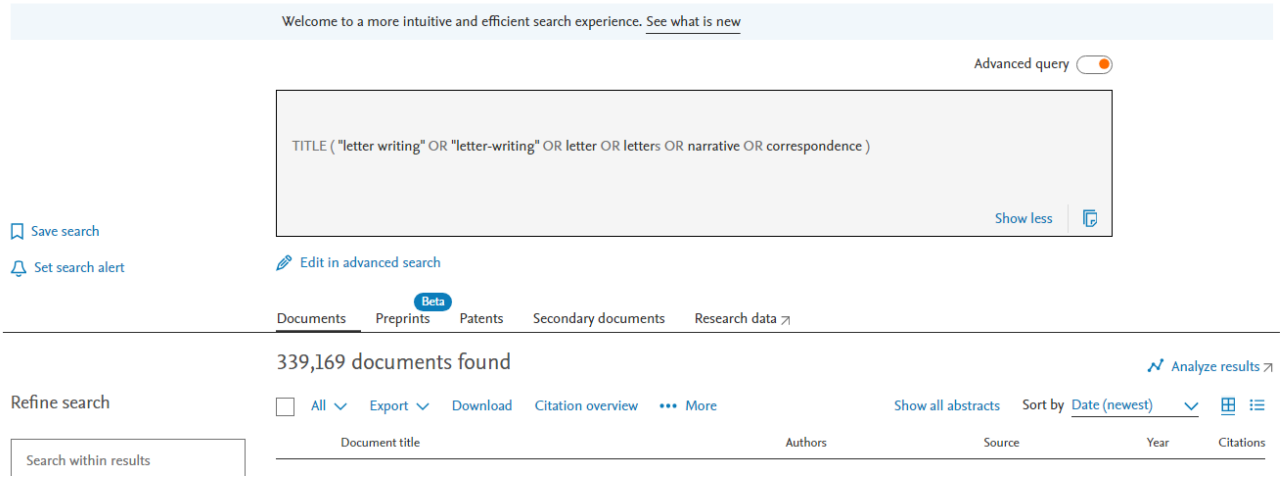
SLR Scopus electronic database search example

An example of an electronic search strategy for SCOPUS. Using search terms and AND/OR Booleans.

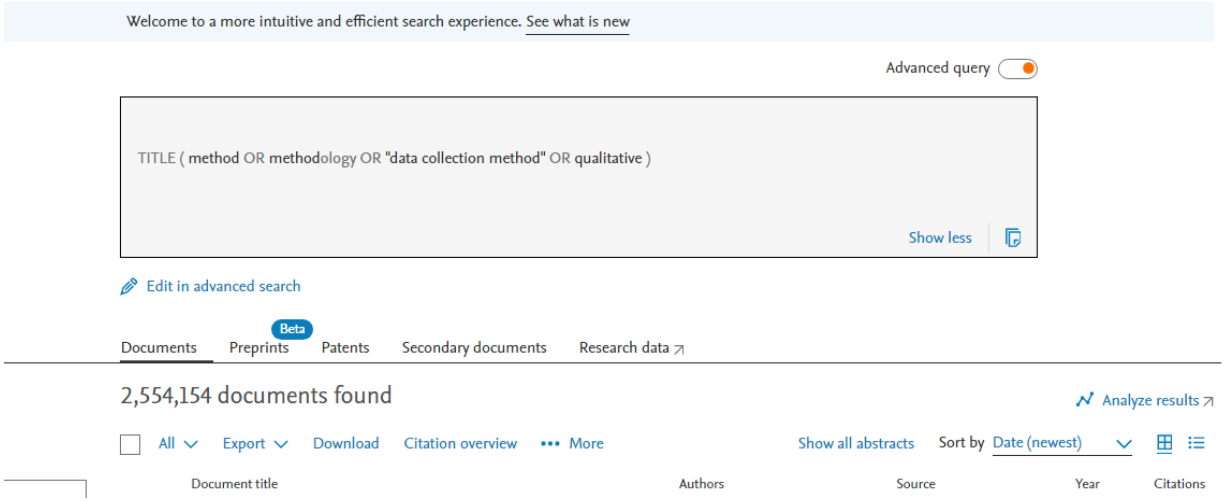
Letters **OR** letter **OR** “letter writing” **OR** “letter-writing” **OR** “correspondence” **OR** “narrative **AND** qualitative **OR** method **OR** methodology **OR** “data collection method”

No mesh terms were used. Searches were limited to titles and journal articles.

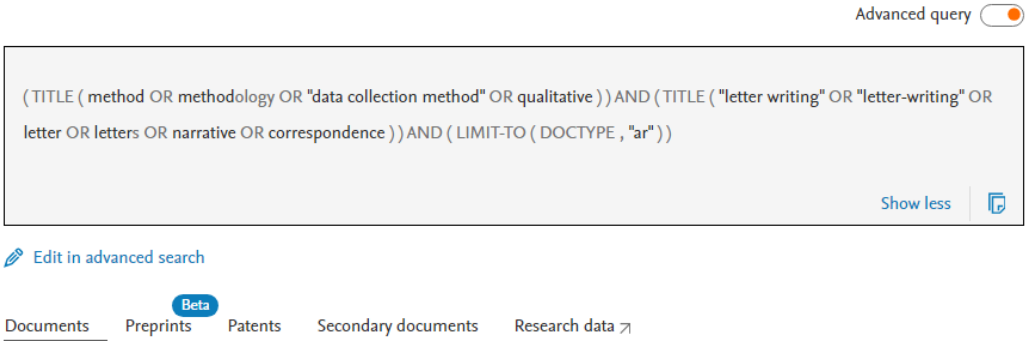
First concept search.



Second concept search**.**



Combined concepts search limited to journal articles.



Appendix C

SLR search results and data extraction.

Paper no.	Authors and title	Study Design	Condition/ or experience being studied	Recruitment/source of letters	Operationalisation of letters	Number of letters	Researcher communication /use of self	Benefits and challenges to using letters
1	Cummings, C. & Gruenert, S. (2011). **The fan letters of Ryan White: a method to promoting prevention**.	**Aim:** To inform the prevention of AIDS through analysing the fan letters to Ryan White **Method:** Qualitative Letters **Analysis:** ? **Epistemology:** ?	The fan letters of Ryan White, a child who died from complications related to AIDS.	Existing fan letters	**Rationale:** To look for themes that could inform AIDS prevention efforts. **Format:** N/A **Length of time to complete**: N/A **Nature of instructions:** N/A **Length of letters:** ? **Who/what directed to:**	**Per participant:** N/A **In total:** ?	**Communication:** N/A **Use of self:** ?	**Benefits:** ? **Challenges:** ? **Recommendations:** ?

					Ryan White			
2	Brown, J., Fowler, S., & Mason, T. M. (2023). **Nurse residents' legacy letters: A qualitative analysis**.	**Aim:** To add to the body of knowledge of nurse residents' perceptions of their experiences and subsequent advice that is worthy of passing along to,future nurse residents. To identify and describe messages communicated in nurse residents' legacy letters at the conclusion of a yearlong nurse residency program at a National Cancer Institute **Method:** Qualitative Letters **Analysis:**	Nurse residents' experiences at cancer institute and advice to next group of residents	There were 73 legacy letters in an existing database on the centre's intranet	**Rationale:** Previously body of knowledge held stories. Letters help to identify advice that is worthy of passing along. **Format:** ? **Length of time to complete:** ? **Nature of instructions:** Message to future nurse residents, reflecting on aspects of the experience such as "what I wish I knew" or "what I learned. **Length of letters**: ? **Who/what directed to**:	**Per participant:** ? **In total:** 73 letters in database, 30 letters randomly selected and used.	**Communication:** N/A **Use of self:** ?	**Benefits:** ? **Challenges:** The written legacy letters were intentionally brief and focused (i.e., "what I wish I knew" or "what I learned"), limiting the interpretation of findings. The addition of in-depth interviews may allow for a richer understanding of the experiences of oncology nurse residents completing the program **Recommendations:** One consideration is to ask nurse residents to label or title their letters with one main take-home point and group

		Thematic analysis **Epistemology:** ?			Message to future nurses.			letters by theme. This can allow for an examination on frequency of access for further exploration on meaningfulness Future research may include exploring the impact on nurse residents reading the legacy letters
3	Mawdsley, A., & Willis, S. C. (2023). **Academic resilience in UK pharmacy education–a pilot study applying love and break up letters methodology.**	**Aim:** The study reported here used love and break-up methodology to explore why pharmacy students report poor academic resilience, why it declines over the four years of study on the Master of Pharmacy (MPharm) degree, and how it is linked to wellbeing	The lived experience of pharmacy students	Purposively, students from the final year of a four year MPharm degree (n=136) at one UK higher education institute were invited to take part in a pilot study using LBM.	**Rationale:** Since resilience is a set of dynamic non-cognitive traits (consisting of self-efficacy, planning, control, composure, persistence), analysis of feelings and emotions about resilience generated through the art of creative and reflective writing where	**Per participant:** 1 letter, but one participant wrote two (one break up and one love letter) **In total:** 8	**Communication:** N/A **Use of self:** The researchers independently analysed the data and then compared codes through reflexive discussion in an iterative process to achieve a consensus in analysis and	**Benefits:** Participants in this study welcomed the cathartic process of reflection LBM allows and expressed that letter writing, reflecting, narrating, listening and discussing within a group of peers had a positive impact on sense of wellbeing, social connection and in itself is a

		Method: Multimethod Focus groups Letters A sample student letter was then read aloud to support participants' understanding of the method and also to provide an example of how the study was exploring the concept under investigation. Once this was completed, participants were given 30 min to write a love and/or break-up letter to their resilience in relation to their curriculum and their experiences			participants outline, explain and make sense of their conceptions of academic resilience (positive and negative) provides a lens through which it is possible to view a participant's underpinning set of ideas and opinions in relation to their experience of resilience. **Format:** ? **Length of time to complete:** 30 minutes **Nature of instructions:** Love and/or break-up letter to their resilience in relation to their curriculum and their		understanding of the themes.	useful method of honest and realistic student-led dialogue which may be useful for pharmacy educators to consider when designing interventions for supporting student wellbeing and academic resilience. **Challenges:** LBM is a method that is potentially uncomfortable to participants and so recruitment to the study was difficult and limited the data and potential saturation of themes. The higher number of female participants may be in part due to the method and

		over the MPharm programme. After working individually on their letter(s), participants were brought together in a group, with each participant reading their letters(s) aloud to the group. While participants were reading out their letter(s), the group facilitator made notes about their content, and then used these notes as prompts to seed further questioning in a focus group. The whole session was audio recorded.			experiences over the MPharm programme. Through the act of writing a letter, a participant details and expresses their feelings and as such this letter writing is a way in which researchers can start to understand collective experience through the production of reflective narratives. This method is both constructivist and constructionist, as an individual uses reflective writing to articulate their feelings and as a group when meaning is explored and co-			also means the findings are female-centric but also the demographics of UK pharmacy students; the undergraduate pharmacy student population of the UK is largely female, with less than a third male. **Recommendations:** The methodology can act as a form of resilience intervention. **Other comments:** Example of a letter before writing

		The letters and the transcript of the focus group acted as the data set and together these were thematically analysed using an iterative comparative process to identify meta-themes. **Analysis:** Thematic Analysis **Epistemology:** ?			constructed in a discussion of the letters written. In this way meaning is constructed of the phenomenon and the reality of it can be understood. **Length of letters:** ? **Who/what directed to:** To their resilience and experience on the MPharm prgogramme			
4	Day, M. C., Hine, J., Wadey, R., & Cavallerio, F. (2023). **A letter to my younger self: using a novel written data collection method to understand the experiences of athletes in Chronic Pain.**	**Aim:** The aim of the current study is to explore the use of an older, wiser, self letter in an athletic population who have experienced chronic pain This study set out to explore	Experiences of athletes in chronic pain	Criterion based purposeful sampling (i.e. to select information-rich cases who met the aims of the study). Letter writing task for study.	**Rationale:** The use of letter writing may provide an alternative platform, which allows the participant more time for contemplation and reflective description. Further, letters addressed to the	**Per participant:** 1 **In total:** 21	**Communication:** N/A **Use of self:** As a research team we then posed these dialogical questions amongst each other, debating excerpts from the letters, and	**Benefits:** The use of a younger self letter provided participants with a known recipient for their writing and participants described their visualisation of the younger self, which provided a powerful embodied

		the use of letters, written in hindsight to a younger self in chronic pain **Method:** Qualitative Letters **Analysis:** Dialogical narrative analysis (DNA) was used to analyse the written letters. This form of narrative analysis focuses not only on the content of stories, but also their effects (Frank 2010). Consequently, the focus is on the relationship between the events being narrated and the event of narration, thus			self do not need to be understood by an 'outsider' and consequently, participants may write in a way that is more intuitive and which resonates with their own language and embodied experiences. The use of an 'older, wiser self letter' draws on what has been learned over time, opening up the opportunity to give back to others in a similar situation. Consequently those experiencing chronic pain may be well placed to explore the value of letters written in hindsight		considering how our discussions of these questions answered the broader aims of the study. In doing this we considered the effects that the letters had on us as the reader and recorded all of our comments. Throughout the analysis we kept procedural memos to record how our ideas changed and developed, providing a trail of our interpretations and linking together ideas from dialogical questions The final stage of our analysis	experience. Rather than suggesting that retrospection is a limitation, what if we celebrated hindsight as a strength of research, for its ability to allow for reflection and consideration of how specific events or experiences are placed within the life story of the athlete? As demonstrated in this study hindsight is a powerful tool, allowing for narrative re-description of events. This does not distort reality but clarifies the meaning and significance of the past. Given that our participants illustrated the lack

		considering what happens as a result of telling the story. **Epistemology:** Ontological relativism (i.e. reality is multiple, created, and mind dependent) and epistemological constructionism (i.e. knowledge is constructed and subjective) Thus narratives are the cultural and social resources from which people construct their personal stories and understand the stories they hear.			**Format:** Email or post. Post offered to remain anonymous. **Length of time to complete:** ? **Nature of instructions:** First provided with a prompt that encouraged them to think about a specific time point for their writing: 'I would like you to think about a time when you would have liked to receive this letter. This could be any time that feels right for you – it could be a time when you were struggling with chronic pain, or a time when you felt like you were		was to write up our interpretations. Here the research team acted as critical friends, continuing to promote debate and discussion as results were written up We open our results section with what may be termed a 'collective letter'. This letter, written using amalgamated participant quotations, illustrates the characterisations, structure, and narrative themes that were evident in the data collected. As a research team	of understanding surrounding their chronic pain, the use of a collective letter may provide validation of their experiences and a sense of belonging **Challenges:** We are also cautious that this method holds the potential to evoke difficult memories. **Recommendations:** It is therefore paramount for researchers to consider how to protect the well-being of participants. This may be challenging given that letters are written in a time and location to suit the participant. Consequently,

					coping well'. The aim of this prompt was to encourage participants to visualise their younger self, moving away from a more abstract image of self to imagining the younger self at a specific point in time. Participants were then instructed: 'Now think about what you would like this letter to say. You might consider: What advice would you like to give to yourself? What would be most helpful or comforting to hear? What would you do differently? What would you encourage yourself to keep		we were deeply moved by the poignant and emotive letters written by our participants. Yet representing the privilege of receiving such letters in a research paper can be challenging. We hope that the use of a collective letter may afford the reader some semblance of what such letter may 'do' for the recipient and encourage our readers to consider what this letter does and how they feel it.	clear indication of the support available must be given (e.g. working hours of the researcher) and sources of further support and referral networks may be provided as a matter of course. As previous authors on letter writing have warned (e.g. Kralik et al.; Harris 2000) the researcher must be sensitive to the needs of participants, individually acknowledging and responding to letters that are submitted. Consequently, this method requires the time, skills, and emotional investment of the researcher.

					doing the same? What would you tell yourself about the future?' Instructions for writing the letter highlighted that participants should not be concerned with spelling, grammar or 'getting it right', but should construct a letter that feels right to them. Further, it was iterated that there was no 'ideal length' for the letter or 'right' way to approach this task. **Length of letter:** participants told no ideal length. **Who/what directed to:** Younger self.			It is also therefore important to consider the well-being of the researcher engaged in a writing project On receiving these letters we could not be morally neutral, value-free, or (as suggested by our ethics board) send a universal debrief template to all participants. Instead, using a reflexive ethical approach (Smith and Sparkes 2014) provided a more appropriate way noticing our reactions to participant letters and responding in an adaptable, responsive, and safe way that paid attention to the potential

								power imbalances between researcher and participant and was sensitive to each unique situation. Letters written in hindsight may be valued not only by the writer, but also by a range of readers (e.g. sport psychologists, coaches, healthcare professionals) as a form of narrative learning and as a source of narrative care for those experiencing similar difficulties. Our study highlights the importance that should be attributed to hindsight and the value of re-describing with

								wisdom and experience. **Other comments:** We open our results section with what may be termed a 'collective letter'. This letter, written using amalgamated participant quotations, illustrates the characterisations, structure, and narrative themes that were evident in the data collected. In writing the collective letter we considered the narrative structure, characterisation, and plot of all of the participant letters to form a template.
5	Burry, K., Beek, K., Worth, H., Vallely, L., & Haire, B. (2023).	**Aim:** To examine how abortion is	Attitudes to abortion in pacific	Existing letters We selected the newspapers in this	**Rationale:** It is important to understand how abortion is	**Per participant:** N/A	**Communication:** N/A	**Benefits:** ? **Challenges:**

	Framings of abortion in Pacific Island print media: qualitative analysis of articles, opinion pieces, and letters to the editor.	framed in print media in the Pacific Islands Our aim was to understand how abortion is framed in media discourse in these Pacific Island countries **Method:** Multimethod Articles, opinion pieces, and letters to the editor We analysed the different types of texts together but note the text type and other important identifying factors **Analysis:** Inductive thematic analysis	island print media	analysis based on the availability of online content published in English.	framed in public forums, such as print media, as such framing could both reflect and influence how abortion is treated in political and legislative contexts, and how abortion is stigmatised Editorials, opinion pieces, and letters to the editor, however, build arguments and promote the opinions of an institution or media outlet (as in editorials), or of an individual (as in opinion pieces and letters to the editor) on a particular topic **Format:** ?	**In total:** 246 articles, opinion pieces, and letters that cover the topic of abortion Proportion of letters not described.	**Use of self:** We note that, while we each have personal and professional relationships with people and organisations in Pacific Island countries, and one of us is currently based in the Cook Islands, none of us identify as Indigenous to a Pacific Island country so write as cultural outsiders.	Texts already collected may not be fully representative of the full scope of views **Recommendations:** ?

		Epistemology: critical feminist research			**Length of time to complete:** N/A **Nature of instructions:** N/A **Length of letter**: N/A **Who/what directed to:** Letter to editors of newspapers			
6	Schmitz, H. P., Mitchell, G. E., & McCollim, E. M. (2021). **How billionaires explain their philanthropy: A mixed-method analysis of the giving pledge letters.**	**Aim:** To investigate a discourse about billionaire philanthropy To analyse letters by Giving Pledge members to Better understand the discourse about philanthropy among the wealthy. **Method:** Mixed method	Philanthropy of billionaires.	Billionaire pledge letters	**Rationale:** We consider the letters not just as vessels of data to derive individual motives, but as social products of, and contributions to elite philanthropic discourse **Format:** ? **Length of time to complete:** N/A	**Per participant:** 1 **In total:** 187 The amount that had been submitted.	**Communication:** N/A **Use of self:** ?	**Benefits:** Beyond the explanations and rationales, the letters portray a nuanced and evolving discourse of elite philanthropy Billionaires may be much less likely to respond to traditional survey or interview requests, which suggests discourse analysis as a

		6 stepped analysis including inductive analysis and statistical analysis. **Analysis:** Content analysis LCA provides a more concise and powerful understanding of the letters than what is feasible and interpretable with qualitative coding and summary statistics alone. **Epistemology:** ?			**Nature of instructions:** N/A **Length of letters:** The average length of the letters is 441.58 words (median: 400 words). **Who/what directed to:** Letter alongside pledge detailing philanthropic causes.			means to reconstruct their philanthropic actions by using publicly available data. **Challenges:** ? **Recommendations:** One could pay greater attention to explanations not or rarely mentioned in the letters. A more complete understanding of this discourse would push beyond this analysis to identify what remains unsaid in this discourse Additional comparisons could also examine the contents of early letters with more recent ones,

								or explore the role of gender or national or cultural context as possible factors shaping differences across pledgers. **Other comments:**
7	Kilgore, C. D., Lehmann, P., & Voth Schrag, R. (2019). **Discourse after a batterer intervention program: A qualitative analysis of "Letters from the future".**	**Aim:** Assess men's (n = 45) responses to a writing assignment completed at the end of a solution-focused Voluntary batterer intervention program Our goal is to better understand how these men use the assignment to present their understanding of their lives, and how that presentation rejects or	Batterer intervention programme	A writing assignment completed at the end of a solution-focused voluntary batterer intervention program.	**Rationale:** The assignment is a way "to elicit the experienced meaning of a future self", then in the present context, BIP participants' letters may reveal the men's ideology: their beliefs, values, commitments, and epistemology. These letters may also reveal something about their future actions **Format:** ?	**Per participant:** 1 **In total:** 46 letters Left with 44 letters, One did not follow several of the assignment instructions, and so was excluded from all analyses (N = 45), and another evaluated	**Communication:** N/A **Use of self:** ?	**Benefits:** ? **Challenges:** It seems likely that some participants may modify their discourse in anticipation of having it read by the BIP practitioner **Recommendations:** ? **Other comments:** People not following instructions/prom

		colludes with common discursive maneuvers that sustain intimate partner violence (IPV) in Anglophone cultures. **Method:** Qual Letters **Analysis:** Content analysis Narrative Analysis We begin with a grounded-theory approach to content analysis (Strauss & Corbin, 1998), discovering thematic patterns in the letters, and aggregating those themes into a conceptual			**Length of time to complete:** ? **Nature of instructions:** The assignment asks the men to imagine a future scenario in which they have met life goals, and to write back to themselves from that perspective BIP participants' letters may reveal the men's ideology: their beliefs, values, commitments, and epistemology. These letters may also reveal something about their future actions **Length of letters: ?**	the participant's present situation, rather than imaginatively projecting a future scenario, and was excluded from some narrative analyses (narrative n = 44		pts – were excluded

		model that covers the widest possible range of responses. We then conduct a narrative analysis, reassessing each letter's narrative structure to find common patterns in the men's understanding of temporality, causality, and agency. Finally, through a comparison between the discourse and narrative analyses, we create a typology of the letters. To ensure that the codes reflected the men's idiosyncratic ways of seeing the world rather			**Who/what directed to:** letter from your future self			

		than other differences in discourse practice, bivariate analyses (t test, ANOVA, chi-square) assessed the relationships between themes and demographic information. The letter analysis proceeded in two phases: a content analysis and a narrative analysis. The analyses employed an inductive grounded-theory approach (Strauss & Corbin, 1998) to draw out patterns in the letters' content rather than risk imposing predetermined						

		discursive structures on the letters. **Epistemology:** ?						
8	Perrot, S., Launay, A., Desjeux, D., & Cedraschi, C. (2017). **Pain patients' letters: The visit before the visit– A qualitative analysis of letters from patients referred to a tertiary pain center.**	**Aim:** To examine the content and format of these letters, for a patient perspective analysis **Method:** Qualitative **Analysis:** Content and semantic analysis **Epistemology:** ?	Letters from patients referred to a tertiary pain center	Purposive sampling Spontaneous letters from patients referred to a tertiary pain center.	**Rationale:** Some patients spontaneously send letters, before the visit, and these letters represent the first contact between the patients and the pain centers. We report a study of the content and format of these letters, for a patient perspective analysis **Format:** Most of the letters (N = 28) were type-written on a computer, 13 were hand-written and 1 on	Per participant: 1 In total: 42 44 had sent a letter before their first appointment . Two were excluded because they were healthcare professionals, thus leaving the sample with 42 letters for analysis. In qualitative studies, the number of participants is generally	**Communication:** N/A **Use of self:** ?	**Benefits:** Personal documents, such as letters, have various strengths: they are stable (they persist beyond the context of their production), contextually relevant and grounded in the context they represent (documents are a type of formal communication that reveal expectations and knowledge of their producers), and provide behind-the-scenes information to which the researchers would not

					an ancient typewriter. **Length of time to complete:** N/A **Nature of instructions:** Data collection was observational and non-participative: no question or query was addressed to the patients (about their reasons for writing a letter or get further information about the contents or for any other reason) **Length of letter:** The length of the letters varied considerably, from 10 hand-written lines to two pages using an Arial 10 font.	determined by purposive sampling, i.e. by the need to cover the range of possible responses (Gaskell, 2000) and to achieve data saturation (Pope et al., 2000; Daly et al., 2007). Participants are thus selected according to predetermined criteria relevant to the research objective. The data we collected in this study were essentially the descriptions by patients in their demand		otherwise be privy (they exist independently and before the researcher seeks and uses them as data) (Love, 2003; Miller and Alvarado, 2005; Prior, 2008, 2011). Letters, and the present study offers a new insight into the representations and meaning-making process that can be accessed through these letters from patients suffering from chronic pain. **Challenges:** Their limitations arise from some of these strengths: they are noninteractive and are not reactive (the meaning cannot be checked with

					Who/what directed to: Patients' letters spontaneously addressed to a pain center, prior to their first appointment.	(including pain, suffering, patient pathway), and how they chose to write and describe their difficulties and their needs to a specialised pain center. Using a pragmatic and flexible approach to sampling, a participant sample was included to ensure that the sample was diverse enough to include experiences of the various types of pain that patients consulting the center may		documents), thus making it difficult to explore original meanings and intents and making document analysis a post-hoc account of previously generated data Female patients and fibromyalgia patients were more likely than other patients to send a letter. Communication by letter is perhaps easier for female than male patients, and it is possible that fibromyalgia patients, with difficult diagnosis and recognition issues, are more likely to want to reinforce their demand personally by letter

						experience, that is, a sample that would consist of participants presenting with characteristic as close as possible of the population studied, i.e. patients consulting the center. Our experience in our center indicated that a three-month period would allow inclusion of letters from forty to fifty newly referred patients and thus a suitable sample		**Recommendations:** ? **Other comments:**

9	Jensen, L. (2014). **User perspectives on assistive technology: a qualitative analysis of 55 letters from citizens applying for assistive technology.**	**Aim:** This study focuses on user perspective on assistive technology and has the following overall aims: ■ To achieve a deeper knowledge about user perspectives on assistive technology in order to develop and enhance the service delivery system of assistive technology for the benefit of the users. **Method:** Qualitative **Analysis:** deductive content analysis and an inductive thematic analysis	Danish citizens applying for assistive technology	Naturally occurring data in the form of 55 letters from 33 Danish citizens applying for assistive technology were Used.	**Rationale:** ? **Format:** ? **Length of time to complete:** N/A **Nature of instructions:** N/A **Length of letters:** ? **Who/what directed to:** Citizens applying for assistive technology were used.	**Per participant:** 55 letters from 33 persons **In total:** 55 **Rationale:** ?	**Communication:** N/A **Use of self:** ?	**Benefits:** ? **Challenges:** ? **Recommendations:** ?

		Epistemology: ?						
10	Cahalane, H., Parker, G., & Duff, S. (2013). **Treatment implications arising from a qualitative analysis of letters written by the nonoffending partners of men who have perpetrated child sexual abuse.**	**Aim:** Attempts to address the gaps in the existing literature by exploring how the nonoffending partners of men who have perpetrated extrafamilial and/or noncontact offenses construct their experiences One of the main objectives was to identify implications for treatment **Method:** Qualitative **Analysis:** thematic analysis	Treatment Implications Arising From a Qualitative Analysis of Letters Written by the Nonoffending Partners of Men Who Have Perpetrated Child Sexual Abuse	Letters written by nonoffending partners were used as the data source Participants were recruited from a 16-week psychoeducational group for Female nonoffending partners in a community forensic psychology service in the northwest of England. As a therapeutic task, group members were asked to write a letter to their partner at the beginning and end of the group, describing their feelings about his offending. The letters were not shared with the	**Rationale:** Letters were used for a number of reasons. The fact that they were written as part of the group minimized the risk of causing unnecessary distress to the women. In addition, Duff (2011) argued that participants might be more honest in letters and more likely to use their own language and focus on issues of personal significance than in an interview. Letters have also been used in previous research. For example, Duff (2010, 2011),	**Per participant:** 1 **In total:** 9 Nine women were recruited from three groups run consecutively over a 24-month period. It was not possible to contact six women from the first two groups as some time had elapsed since the groups' completion. This limited the sample size	**Communication:** N/A **Use of self:** A variety of means were used to guard against researcher bias throughout the analysis and to validate the findings. Two letters were coded independently by a colleague experienced in using the same methodology, after which the two sets of codes were discussed to ensure that they accurately reflected the data. In addition, both	**Benefits:** ? **Challenges:** Some detail might have been lost by the fact that letters formed the data source, removing the opportunity for the researcher to probe or clarify ambiguities. Furthermore, participants' ability to articulate their experiences in writing will have been influenced by their educational/literacy levels. In addition, the fact that women were aware that their letters would

		The study was conducted using thematic analysis through a social constructionist lens. Thematic analysis was chosen because it is a flexible qualitative method that analyzes patterns across a data set (Braun & Clarke, 2006). It allows themes to be identified at both a manifest and latent level, the latter enabling the researcher to interpret the beliefs and assumptions underlying the surface content of the data. Social constructionism is concerned with understanding		perpetrators, but they supplemented psychometric assessment data and allowed facilitators to determine whether there had been any shift in how women perceived their partner's offending over the course of the group. It was decided to focus on the initial sets of letters to understand the experiences of nonoffending partners prior to intervention.	and Webster and Beech (2002) analyzed the victim apology letters of male perpetrators of CSA, demonstrating their value as a source of data. **Format:?** **Length of time to complete:** ? **Nature of instructions:** As a therapeutic task, group members were asked to write a letter to their partner at the beginning and end of the group, describing their feelings about his offending **Length of letters:**?		of the researchers' supervisors checked four transcripts to provide consensus that relevant information was included at the coding stage. Both supervisors worked in the Experiences of Nonoffending Partners 727 service where the group was run and therefore had a good knowledge of the context of the group. Finally, initial themes were presented to both supervisors and revised based on feedback. Final thematic maps were subsequently	contribute to an assessment of their capacity to protect their children might have influenced how open they were. **Recommendations:** The research analyzed data that had been gathered for clinical purposes. Thus participants might have been mindful of what they wrote, in case it adversely impacted the outcome of their assessment. Future research could overcome this by gathering data solely for research purposes and therefore protecting participants' anonymity, increasing the likelihood

		the way in which people describe their world (Gergen, 1985). It posits that reality is constructed through social interactions and Experiences of Nonoffending Partners 725 the language people use, and it views historical, social, and cultural factors as central to shaping each individual's construction of reality (Burr, 2003). **Epistemology:** social constructionist framework.			**Who/what directed to:** A letter about their partner and their feeling about his offending		reviewed and discussed in supervision. In addition, the first author maintained a research journal to ensure ongoing reflexivity throughout the research process.	of them being open and honest and therefore reducing the risk of bias in the data.
11	Zannini, L., Cattaneo, C., Brugnolli, A., & Saiani, L. (2011). **How do healthcare**	**Aim:** The aim of this study is to describe participants' responses to	An 18-month mentoring programme (comprising 1500 hours	Participants who attended a mentoring/preceptoring programme	**Rationale:** The researcher was informed by the action-research assumption that development of	**Per participant:** 1 **In total:** 27	**Communication:** N/A **Use of self:** Before analysing the	**Benefits:** ? **Challenges:** ?

	professionals perceive themselves after a mentoring programme? A qualitative study based on the reflective exercise of 'writing a letter to yourself'.	a reflective practice exercise about a mentoring programme **Method:** After writing the letter to themselves, the participants were invited to read it, in a large group setting. Only about one-third of the letters were shared in the large group session. At the end of the session all the participants gave the original copy of their letter to the researcher. **Analysis:** Phenomenological-hermeneutic analysis **Epistemology:** ?	of teaching) was started at the Faculty of Medicine, University of Verona (Italy) in collaboration with the Provincial Health System of Trento (Italy), in the year 2000.		practical knowledge in a professional community calls for an inquiry that improves self-knowledge, which involves selfreflection in dialogues (Polit & Beck 2004). To achieve these aims, storytelling and written narratives are widely considered ideal strategies **Format:** Hand written **Length of time to complete:** ? **Nature of instructions:** ? **Length of letters:** ? **Who/what directed to:**	**Rationale:** Data were gathered from all the participants who attended the last unit of the mentoring programme (n = 27, one absentee)	letters, the two researchers made explicit their preconceptions about the experience of attending a mentoring programme. All the steps of data analysis were performed at first individually and then were discussed collegially by the researchers, until an agreement was found. In each step of the analysis the researchers kept a reflexive attitude toward the phenomenon under study, considering continuously alternative interpretations	**Recommendations:** Reflective writing can be a useful tool both to understand mentoring programmes participants' lived experience and to promote further learning. • Looking for a sense of professional and personal growth, especially through writing exercises, can be a valid strategy to evaluate a mentoring programme. In fact, this change reveals reflexivity that is a core attitude in mentoring. • Reflective writing exercises may promote the healthcare professional as a reflective

					Write a letter to yourself		of the participants' phrases and finally grounding their analysis on the letters' texts (Mays & Pope 1996).	practitioner, both as an educator (e.g. mentor, preceptor), and, more generally, as a clinician**.** **Other comments:** After reading and sharing emotions, participants were given the choice to give their letter to the course organizers or to keep it for themselves.
12	Furman, R., & Shukraft, A. (2007). **A qualitative study of letters to President Kennedy from persons with mental illness and their families: Using the research poem in policy oriented research**.	**Aim:** An analysis of letters sent to President John Using the Research Poem regarding the formulation of mental health policy during the early 1960s. The article seeks to present the experiences of mental health consumers and	The experiences of mental health consumers and their families-shapers and receivers of mental health services that are infrequently given voice.	For five days, the researcher explored numerous files containing thousands of pages of documents relevant to mental health policy from 1960-1963. Some of the most powerful qualitative materials consisted of letters written to the president. These letters were written in response	**Rationale:** N/A **Format:** About half of the letters were hand written, the other half were typed **Length of time to complete:** N/A **Nature of instructions:** N/A	**Per participant:** N/A **In total:** Files consisted of one hundred and seventeen letters to President Kennedy. Letters were chosen if they met the	**Communication:** N/A **Use of self:** ?	**Benefits:** ? **Challenges:** ? **Recommendations:** ? **Other comments:**

		their families-shapers and receivers of mental health services that are infrequently given voice. **Method:** Qualitative Research poem **Analysis:** ? The author analyzed the data for themes using traditional open and axial coding methods. Research poem Data will be presented in the form of three types of research poems: free verse, the pantoum, and tanka		to proposed mental health legislation	**Length of letters:** ? **Who/what directed to:** President Kennedy	following criteria: 1) they were legible; 2) they contained the authors' perspective about mental illness vis-A-vis social policy 3) they were written by a mental health consumer or a family member of a consumer; 4) the documents contained enough material to be suitable for the creation of a research poem; and 5) they contained enough af fective materials to		

		Once themes were identified, the researcher undertook the process of representing some of the observed themes in different poetic forms. No hard and fast rules were strictly followed in deciding how to present a letter in one form versus another; the researcher relied upon his sense of the data and the media. **Epistemology:** ?				present the lived experience of the author. A total of 20 letters met these criteria. From these letters, a subset of six was chosen to be analyzed and presented via poetic Using the Research Poem 87 re-representation. A subset of 6 letters were chosen		
13	Timmis, M. A., Pexton, S., & Cavallerio, F. (2022, December). **Student transition into**	**Aim:** Aimed to understand the aspects supporting or hindering transition into HE for sport and	Aspects supporting or hindering transition into HE	SES students were invited to participate in Phase 1 of the study during the first week of teaching commencing	**Rationale:** Kress et al. (2011) described letter writing as an activity that allows problems to be externalised,	**Per participant:** 1 **In total:** 58	**Communication:** N/A **Use of self:** Both the second and third authors	**Benefits:** ? **Challenges:** ? **Recommendations:**

	higher education: Time for a rethink within the subject of sport and exercise science?.	exercise science students **Method:** Qualitative Following the development of a single composite version of an "Older, wiser self letter" to represent the identified themes, this resource was integrated into our institution's pastoral care resources and specific sessions where personal tutors connected with their tutees. Member reflections were completed with students to gather feedback on the effectiveness of this resource **Analysis:**			encouraging reflection and providing an opportunity to learn from experience **Format:** ? **Length of time to complete:** 20-30 minutes whilst in class **Nature of instructions:** "Older, Wiser Self Letter" Participants were provided with written guidance on letter writing (e.g., not to worry about grammar or spelling; asking questions such as "What would you like to say to your younger self?," "What		are qualitative researchers with backgrounds in sport coaching and sport psychology. The second author is a postgraduate research student, who had previously engaged with thematic analysis as a student, whilst the third author is an academic with expertise using RTA. The first author instead came from a post-positivist background, related to their expertise in biomechanics, and covered the fundamental role of critical friend (i.e., a person	Composite letter to be shared with community researched. Following re-examination of the letter, students' responses agreed it was a valuable resource as a prompt for discussion, providing a shared "experience" from which members could compare and contrast their own experiences. We have since integrated the letter more frequently into community and individual personal tutor sessions as a mechanism to initially prompt discussion with students Other comments:

		Reflexive thematic analysis. During Phase 2 of the project, our findings were represented using what is known as a "composite first-person narrative" (Biglino et al., 2017), which is an amalgamation of our participants' voices into one story. Thematic analysis is an analytical approach that allows to identify repeated patterns in written data (Braun and Clarke, 2021). **Epistemology:** Study was underpinned by			would be most helpful to hear?" Described letter writing as an activity that allows problems to be externalised, encouraging reflection and providing an opportunity to learn from experience. **Length of letters:** ? **Who/what directed to:** students wrote to their younger self, providing guidance on how to successfully transition into HE.		who listens to a researcher's interpretations and offers critical feedback, encouraging reflexivity; Smith and McGannon, 2018).	The composite letter was portrayed in the form of an "Older, Wiser Self letter" itself, where a student advises their younger self on how to make the most out of their degree, successfully transitioning into HE and avoiding setbacks. Using quotes from the different themes identified, the letter aimed to portray participants' voices in a form that is closer to data collected. Whilst we were aware of existing critiques to composite representation of research findings as losing the uniqueness of each human being' voice, we agree with Hollowell (2017)

		an interpretivist paradigm, with a relativist ontology (i.e., psychosocial reality is multiple and mind-dependent) and a social constructionist epistemology (i.e., knowledge is co-constructed; Sparkes and Smith, 2013 In line with the aim of understanding students' experiences, the present study was underpinned by an interpretivist paradigm, with a relativist ontology (i.e., psychosocial reality is multiple and mind-dependent) and a social constructionist epistemology						who states that composite characterisation allows "to compress documented evidence from a variety of sources into a vivid and unified telling of the story". Moreover, keeping in mind the applied aspect of this second phase, for us it was paramount to show our findings in a way that allowed to show "the complexity and multidimensionality of these phenomena in a manner that evokes emotion and provokes action" (Sandelowski and Leeman, 2012, p. 1405) The reciprocal open dialogue

		(i.e., knowledge is co-constructed; Sparkes and Smith, 2013). T						with students was fundamental to how we understood the member reflections. Their reflections prompted our own reflections of phase 2, specifically the content of the letter, its use, and how the students felt about it. The composite letter continues to be used as part of our institution's pastoral care resources and specific sessions where personal tutors connect with their tutee. Future research will investigate how the use of pre arrival (pre-entry) resources (based upon the themes identified in this current research) facilitates

								transition into HE – Nicholson (1990) termed this the preparation phase; we propose that such pre arrival resources may serve to start the process of transitioning into HE earlier and engage students more effectively in the preparation phase. Themes have been developed into digital resources for students to engage with prior to arriving in HE. During welcome week, we are creating space for students to explore the themes of the letter, consider the results from any diagnostic assessments completed and meet subject

								specific professional staff members.
14	Abnett, H. (2023). **Epistolizing accountability: a critical exploration of INGO annual report leaders' letters.**	**Aim:** How International non governmental organisations (INGOs) communicate their activities and achievements. In doing so, the study seeks to increase our understanding of INGOs' accountability practices **Method:** Qualitative **Analysis:** Reflexive Thematic Analysis. **Epistemology:** ?	'leaders' letters' (the letters that many charities include at the beginning of their Annual Reports and Accounts)	This study took a purposive sample of 39 INGOs that meet the definition above, and published one or more leaders' letters within their Annual Reports and Accounts published between the years 2015-2018	**Rationale:** These letters are of particular interest as they are located within a grey area between formal and informal reporting. This research chose to use secondary sources in the form of the leaders' letters for three reasons: 1) as a way of considering "natural" rather than "manufactured" data (Silverman, 2007; Ho et al., 2021); 2) to enable the collection of data from a wider pool of organisations;	**Per participant:** N/A **In total:** 90	**Communication:** N/A **Use of self:** ?	**Benefits:** ? **Challenges:** As Ho et al. (2021) note, a key weakness of documentary analysis may be that documents often reflect the perspectives of "elites" rather than others. Nevertheless, by paying attention to the "silences" (Ho et al.,2021), this study considers how the voice of people in Africa, Asia, Latin America and Oceania are made absent by these letters The focus on letters limits the questions that can be asked of this data. The

					and 3) for ethical and practical reasons related to the availability of data. **Format:** ? **Length of time to complete:** N/A **Nature of instructions:** N/A **Length of letters:** ? **Who/what directed to:** 'leaders' letters' (the letters that many charities include at the beginning of their Annual Reports and Accounts)			paper is not able to empirically explore the motivations or directly consider the thoughts, opinions, approaches or behaviours of INGO staff or volunteers, instead considering questions through the theoretical constructs of field theory and habitus. This necessarily raises a number of further questions that future primary research may help to answer This paper also recognises that representation of constituents' voice and agency may not be best achieved through such documentation as the leaders'

								letters studied within this research. INGOs themselves have adopted other strategies to reflect constituent voice, such as through co-producing news stories **Recommendations:** ? **Other comments:** Almost all are one-page documents, and less than 1,000 words (with four exceptions), with a median letter length of 483.5 words. The modal group is between 201 and 300 words
15	Hänninen, V., & Sools, A. (2022). **Cultural story models in making sense of**	**Aim:** What kinds of stories do people in Finland and Greece	Cultural story models used by lay people in Finland and	Letters written for study. Convenience sampling via the networks of the	**Rationale:** ? **Format:** Qualtrics - typed	**Per participant:** 1 **In total:** 67	**Communication:** N/A **Use of self:** ?	**Benefits:** This study's main strength lies in its access to lay people´s views of the post corona

	a desired post-corona world.	construct to make sense of desirable personal and societal changes that emerge from the corona pandemic, and how do these stories relate to culturally salient story models?” **Method:** Mixed method Letter from the future creative writing exercise Survey - ten questions (open and closed) about how the coronavirus outbreak has affected participant’s life as well as demographics and participant’s attitude to the future (hope and uncertainty attitude)	Greece to make sense of desirable personal and societal changes in light of the corona pandemic	researchers in the consortium with snowball sampling through participants who were asked at the end of the Survey to further distribute the call for participants. Additionally, calls in newsletters were aimed at recruiting specific groups (Dutch Catholic Association for Elderly people, KBO; a professional network of psychologists in the Netherlands)	**Length of time to complete:** Participants could log out of the study at any time and continue writing at a later time. Completion of the survey typically took between 20 and 60 min, depending on how elaborate they decided to write **Nature of instructions:** The topical domain of the desired future was specified as a moment in time when the current coronavirus outbreak had ended. Second, participants were encouraged to use their imagination and			future, while they themselves were amid the pandemic. They do not represent professional scenarists or social scientific views. It has been interesting to see that letter writers clearly situate their personal future in the broad social context **Challenges:** The challenge of providing sufficient guidance towards narrative (experiential, detailed) writing in an online environment. The disadvantage of the elaborate instruction is its difficulty and length, which likely has contributed to the high drop-out rate.

		Analysis: Narrative analysis. **Epistemology:** ?			focus on possibilities by asking to Remember that it is about a future which has not occurred yet. Consider it an opportunity to think about possibilities to transform your own life and the world around you for the better. Third, similar to the original instruction, the chosen time and place in which the desired future took place were not predetermined but left open for participants themselves to imagine. This openness allowed insight into the way participants themselves situate a post-pandemic future			Finally, a methodological note on the mapping of our story types to cultural story types and among them to master and counter narratives is in order. As we stated in the introduction, narrative psychology asserts that in forming their narratives people draw on socio-cultural resources. This does not mean they do it consciously (although that may happen) or that they express the “source” of their own story. The idea of “drawing on” is thus not possible to prove as true. The farthest we can get is to point

					temporally and spatially. Fourth, participants were encouraged to engage in a sensory exploration of their immediate surrounding of their future world What do you see, feel, hear and smell? Then their attention was turned to the future world at large (community, society, humanity, the planet) by asking Do you notice anything about how society or nature are functioning now that the corona outbreak is over? Fifth, attention was brought to the future self with prompts such as What are you			out the similarities to other stories. This point turned out to be even more difficult concerning the identification of master and counter narratives, as this type of analysis relies heavily on positioning by the writers. In the relative absence of such explicit positioning (due to the nature of letters as opposed to interview data), we introduced the strategy of comparison of story logic across the types, thereby adding etic analysis to an initial emic analysis of countering movements. As Hyvarinen ¨ et al. (2021, p. 103) note, “master narratives seem

					feeling, thinking, and doing? How are you dealing with opportunities and setbacks on a specific day, moment or event? Sixth, participants were asked about the pathway that led to the future just described with an openness to the agency involved in creating that future How did this future come into being, who or what has contributed to making those changes possible? And allowing for participant's own evaluation about the pathway How do you look back on this path to the future? Finally, the participant			to be difficult to find as articulations, and they are therefore often inferred by the researcher and rely on their cultural competence". Not explicitly said – but participants not following instructions. Although the instruction was to write a letter from a desirable future, some writers depicted the post-corona world in mostly (albeit not always solely) negative terms, emphasizing that negative developments – such as materialism or injustice – persist and are even aggravated because of mankind's inability to learn

					was asked to send a message to an audience of their own choice in the present Rationale: Overall, two design criteria played a role in this elaborate description: (a) the dual focus of the study on future self and world, and (b) the challenge of providing sufficient guidance towards narrative (experiential, detailed) writing in an online environment. The disadvantage of the elaborate instruction is its difficulty and length, which likely has contributed to			**Recommendations:** ?

					the high drop-out rate. **Length of letter:** we decided to limit the sample to letters containing at least 300 words (41 letters, length of which varied from 300 to 1324 words) **Who/what directed to:** The Letter from the Future exercise was used to elicit participant's ways of envisioning their desired post-Corona life and world. The idea is to imagine traveling to a desired future in a time machine and write a letter from that future retrospectively			

					back to the present.			
16	Gross, J., Davids, T., Sools, A., & Saghai, Y. (2023). **Covid-19 and the politics of hope: A comparative analysis of Greek and Ecuadorian letters from a desired post-pandemic future.**	**Aim:** People living in a range of countries in Europe, North and South America, Asia, and Africa were invited to imagine what the future could look like: in particular, to imagine a desirable future. In this paper we are specifically interested in what these imaginaries show about one particular relationship between the present and the future: a relationship **Method:** Qualitative **Analysis:** Whilst these letters could be	Do personal imaginations of a desirable post-Covid future express hope, and if so, in what ways is this hope political?	This paper belongs to a larger project, to which this special issue is dedicated. The overall data consist of 277 letters from writers residing in 33 countries that were collected between April and July 2020	**Rationale:** We regard this type of approach – data collection open to multiple contexts and scales of participants' desired futures, and multiple possible routes to achieving them – as specifically well-suited to investigating the political characteristics of people's hopes **Format:** ? **Length of time to complete:** ? **Nature of instructions:** The brief we provided to our participants was designed to be	**Per participant:** 1 **In total:** 105 (subset of letters from Ecudor and Greece) Suitably sized data set for the purpose of our analysis	**Communication:** N/A **Use of self:** ?	**Benefits:** Enabling J. Gross et al. Futures 149 (2023) 103115 10 opportunities for people to explore desired futures within deliberately 'open', creative spaces, such as those offered by the Letters from the Future approach – and perhaps particularly when used in groups, in combination with more dialogic and deliberative methods – has the potential to make distinctive contributions to understanding people's hopes in more nuanced ways, including the ambivalence that may characterise them. This could

		analysed in many ways, the two overarching research questions for this paper are, do these letters express hope? And, if so, in what ways is this hope political? For the purposes of analysing the data, the first of these questions was divided into two sub questions (1a and 1b), and the second into four (2a, 2b, 2c, 2d). "In what ways does this letter…" 1a)…demonstrate hope? 1b)…demonstrate despair, fatalism or hopelessness? 2a)…demonstrate hope for a return to 'normal', or the status quo ante?			deliberately 'open' in the range of post-Covid futures that could be imagined. Participants were invited to imagine a desirable future. We regard this type of approach – data collection open to multiple contexts and scales of participants' desired futures, and multiple possible routes to achieving them – as specifically well-suited to investigating the political characteristics of people's hopes. **Length of letters: ?**			include (though should not be reserved to) use within the explicitly 'political' context of electoral politics, in which the classic methods employed for gleaning political attitudes and preferences – opinion polling and focus groups 'market testing' policies and politicians – offer only very limited insight into the texture of people's hopes for the future. Part of the value of the Letters from the Future method is precisely the creative possibilities it offers. It does not seek to merely solicit currently and consciously

		2b)…demonstrate hope for change? 2c)…indicate how the desired future will be brought about? What are the processes, mechanisms or actions? 2d)…indicate who are the 'actors' by whom the desired future will be achieved? We read each letter as a whole, and used Atlas.ti qualitative data analysis software to code phrases, sentences or paragraphs. The data was initially analysed with six codes, corresponding to the questions above: 'hope', 'despair', 'return			**Who/what directed to:** Letters from the future Participants are instructed to imagine travelling to a desired future in a time machine, and to write a letter back to the present.			held beliefs and attitudes, as an opinion poll might; but invites responses through which participants may find out about themselves and their ideas. Understanding – and supporting – the conditions through which people discover and articulate what matters to them is an extremely important task, and one which receives surprisingly little attention (Wilson et al., 2022) **Challenges:** A limitation of our study has been the restricted insight our data can provide regarding the specific conditions,

		to normal', 'change', 'mechanisms' and 'actors'. A thematic analysis (Braun & Clarke, 2006) was then conducted within each of the six code groups, to draw out key themes. The findings from the Ecuadorean and Greek letters were then compared. **Epistemology:** ?						resources and experiences that have influenced our participants' hopes. Studies building on the approach taken here could valuably combine a version of Letters from the Future with methods including focus groups, interviews, ethnography and social media analysis. In doing so, such research has the potential to make valuable contributions to the emerging body of literature on the 'political economy of hope' – by combining detailed analysis of the conditioning of present hopes, with creative explorations of possible and

								preferred futures. This work could be developed in relation to specific issues, such as people's trust in existing political institutions to enable desirable futures; or by addressing more open-ended questions regarding the conditioning and possibilities of hope within particular communities or populations **Recommendations:** there is potential for combining Letters from the Future with other modes of data collection – including interviews, focus groups and ethnography – making possible different kinds of knowledge claim

								to those we are making here Previous uses of the method demonstrate how it generates data in ways that reflect people's real experiences and views whilst also enabling creativity (Sools, et al., 2017; Triliva, et al., 2020). Indeed, the method deliberately invites creative – even playful – responses What we can suggest, however, is that in a small way at least, the further expansion of creative research practices may be able to contribute to the development of such creative democratic

								practices. This could include variations on this project's use of Letters from the Future – or, to give another example, the methods of participatory, verbatim theatre used by Gallagher et al., (2020) in researching young people's capacity for "radical hope" – used in a variety of contexts. These creative approaches to research, to which many others could be added, each have their own specific affordances for holding open a "space for political imagination" (Gross, 2021).

								Studies building on the approach taken here could valuably combine a version of Letters from the Future with methods including focus groups, interviews, ethnography and social media analysis. In doing so, such research has the potential to make valuable contributions to the emerging body of literature on the 'political economy of hope' – by combining detailed analysis of the conditioning of present hopes, with creative explorations of possible and preferred futures. This work could be developed in

								relation to specific issues, such as people's trust in existing political institutions to enable desirable futures; or by addressing more open-ended questions regarding the conditioning and possibilities of hope within particular communities or populations.
17	Cahalane, H., & Duff, S. (2018). **A qualitative analysis of nonoffending partners' experiences and perceptions following a psychoeducational group intervention.**	**Aim:** explore the experiences of NOPs, as well as their perceptions of themselves, their partner's offending, and their relationships, after completion of a psychoeducational intervention. The current study was a	The experiences and needs of nonoffending partners (NOPs), whose partners have perpetrated child sexual abuse (CSA)	Participants were recruited from a 16-week psychoeducational group for female NOPs in a community forensic psychology service in the Northwest of England As a therapeutic task, group members write a letter to their partner at the beginning and end of the group,	**Rationale:** In the current study, the fact that they were written as part of the group was felt to minimise the risk of causing unnecessary distress to the women. It was also consistent with the study's social constructionist	**Per participant:** 1 **In total:** 12 Any woman who met the group's clinical inclusion criteria and had completed the post-group letter-	**Communication:** N/A **Use of self:** ?	**Benefits:** In the current study, the fact that they were written as part of the group was felt to minimise the risk of causing unnecessary distress to the women. It was also consistent with the study's social constructionist framework as it was felt the letters would

		follow-up to Cahalane et al.'s (2013) study, and sought to explore how NOPs construct their experiences following completion of a psychoeducational group intervention. The main objectives were to explore any potential changes in women's experiences and perceptions compared to pre-intervention themes, and identify any potential outstanding clinical issues. **Method:** Qualitative **Analysis:** Thematic analysis		describing their feelings about his offending. The letters are not shared with the perpetrators: they supplement psychometric assessment data and help facilitators to determine whether there has been any shift in women's perceptions over the course of the group.	framework as it was felt the letters would contain women's own language, rather than being potentially shaped by interview questions. **Format:** ? **Length of time to complete:** ? **Nature of instructions:** As a therapeutic task, group members write a letter to their partner at the beginning and end of the group, describing their feelings about his offending. **Length of letters:** ?	writing task was deemed suitable for the study.		contain women's own language, rather than being potentially shaped by interview questions. **Challenges:** Thus, perhaps the letters, although insightful, were limited in their ability to reflect women's own perceptions of their experiences. In addition, they only represent a snapshot immediately after women completing the intervention in a safe group environment, with ready access to both peer and professional support. It is possible that the women will encounter more challenges as they move on

		Epistemology: Social constructionist			**Who/what directed to:** Letter to their partner (they do not get shared with the perpetrator)			from the group and try to apply their theoretical knowledge. Their assertiveness and intentions may be resisted by their partners, they may lose motivation, or they may slip back into old roles and patterns (e.g. the disempowered, dominated, weaker partner) in their relationships. However, an alternative method such as interviews would have had its own limitations. **Recommendations:** ?
18	Laughey WF, Brown MEL, Dueñas AN, et al. **How medical school alters empathy:**	**Aim:** Primary research question was how do senior medical students	Understand how students feel about empathy for patients by the time	Data were collected at the Hull York Medical School (HYMS), during the academic year 2019-20	**Rationale:** LBM is a creative way to understand participants' relationships with the concept	**Per participant:** 2 write both a love and a break up letter to empathy for	**Communication:** N/A **Use of self:** Through reflexive	**Benefits:** Love and break up letters call for heightened, figurative language, here including

	Student love and break up letters to empathy for patients.	characterise their changing relationship with the concept of empathy for patients? Our aim is to explore how their feelings about empathy change as they progress through medical school. **Method:** Multimethod Letters and focus group **Analysis:** Reflexive thematic analysis Focus group transcripts and love and break up letters were analysed together. **Epistemology:** Adopting a constructivist paradigm	they reach the senior years of medical school		under discussion, including affective domains. We reasoned that LBM would help us understand the positive and negative feelings that students acquire about empathy as they progress through medical school. The negative, or 'break up', feelings, in particular, may provide useful insight into the concept of ethical erosion.2 As such, LBM suits the requirements of this study, which aims to understand the changing nature of student relationships with the practice of empathy for patients.	patients **In total:** 20	conversations, we clarified our personal interpretations of empathy, agreeing on a broad-based view, including affective, cognitive, action and moral components. All of these formed the sensitising concepts10 around which we conceived our focus group questioning and data analysis: for example, although rarely needed, we devised focus group question prompts in case spontaneous discussion waned, which centred on	personification, metaphor, hyperbole, even poetry. This writing is more colourful. It elevates interest and engagement, fuelling discussion around what could otherwise be an abstract topic. The letters also engaged us in our research analysis. Creative writing communicates richer messages and richer messages translate to richer data for analysis. LMB allows all group members to have an initial voice, mitigating a limitation of focus groups that quieter members may be over-shadowed by

					Format: ? **Length of time to complete:** At the beginning of the focus group, participants were given 30 minutes to write both a love and a break up letter to empathy for Patients **Length of letters**: ? **Nature of instructions:** Please write a love-letter to the concept of 'empathy for patients'. Try to pretend that 'empathy for patients' is the entity you are in love with and tell the concept what you like and love about it and why.		these concepts.	talkative ones.59 Reading letters aloud also acts as an icebreaker for the discussion to follow. Finally, the letters supplement the focus group transcripts: they provide increased data for analysis. **Challenges:** Of course, there are limitations. By their nature, love and break up letters are dichotomous, risking a focus on polar opposites and sacrificing shades of grey between. Focus group moderators need to be mindful of this. Moderators also need to be sensitive to participants who are wary of creative writing

					Try to be reflective about the points you make and link them to your own experience. Write this love letter below. If you need more space, feel free to expand beyond this paper: Please now write a break-up letter to the concept of 'empathy for patients'. Try to pretend that 'empathy for patients' is the entity you are breaking up with and tell the concept what you don't like and might want to change about it and why. Try to be reflective about the points you make and link them to your own experience. Write this break-			and embarrassed to read their letters. On a practical level, the writing task extends the duration of the focus group, adding 20-30 minutes in this study **Recommendations:** ?

					up letter below. If you need more space, feel free to expand beyond this paper: Rationale: LBM is a creative way to understand participants' relationships with the concept under discussion, including affective domains. We reasoned that LBM would help us understand the positive and negative feelings that students acquire about empathy as they progress through medical school. The negative, or 'break up', feelings, in particular, may provide useful			

					insight into the concept of ethical erosion.2 As such, LBM suits the requirements of this study, which aims to understand the changing nature of student relationships with the practice of empathy for patients. **Who/what directed to:** The concept of empathy for patients			
19	Sools, A. M., Tromp, T., & Mooren, J. H. (2015). **Mapping letters from the future: Exploring narrative processes of imagining the future.**	**Aim:** to study empirically what happens when we ask participants to engage in the practice of imagining the future through narrative. The goal of this endeavour is to map a	To explore the human capacity of imagining the future	We used a variety of sampling methods. We distributed calls in various newsletters and through social media and used snowball sampling by asking students to write letters and recruit friends, relatives and acquaintances.	**Rationale:** From a narrative perspective, letters from the future are considered to be indicative of a variety of forms through which human beings construct and understand their future	**Per participant:** 1 **In total:** 480	**Communication:** N/A **Use of self:** ?	**Benefits:** The instrument (letters from the future) seems promising in this respect, because the instruction encourages writers to 362 Journal of Health Psychology 20(3)

		variety of forms of imagining the future. W Mapping the variety of forms of imagining the future is particularly relevant in the context of health psychology. The project could expand the possibilities of mainstream health psychology by including a narrative perspective and of narrative psychology by including the future more explicitly. **Method:** Qualitative **Analysis:** Narrative, content and comparative analysis			selves and worlds. This is consistent with an interpretive approach to understanding the human mind, which offers an alternative for the current dominant causal-explanatory approach in psychology. **Format:** Web based tool **Length of time to complete:** ? **Nature of instructions:** The two most important adaptations of the instruction were the following: (1) more emphasis on the use of narrative particulars to			provide narrative detail. Moreover, as the combination of evaluative and imaginative components suggests, narrative futuring can be viewed as the future-oriented counterpart of life-review, and the Letter from the Future as a prospective reflection instrument. In contrast to the common notion in narrative psychology that examining life necessarily takes place by looking back, looking forward can equally serve the purpose of reflecting on what life is worth living. Moreover, the letter exercise can be a powerful way of not only

		Epistemology: ?			invoke the experienced meaning of the future self (Crites, 1986; Erikson, 2007), for example, to vividly imagine a particular situation at a particular moment in the future in which something positive has been realized and (2) leaving the particular audience to whom the letter had to be addressed open to choice (originally the audience was the group of other participants in the reminiscence course). **Length of letters:** ?			reflecting on but also encouraging living according to one's values. More specifically, the dialogical component could be considered in terms of the dialogical relation between future self and present self; this could be an interesting entry to study self-development **Challenges:** However, the types with little or no narrative imagination show that the Letters from the Future instrument not necessarily elicits narrative imagination of a future self. Following Tom Wengraf (2001), we suggest that

					Who/what directed to: we asked participants to write a letter from the future. The letter exercise was an adaptation of a future-oriented exercise that was developed notably as part of a reminiscence course for older Dutch persons with minor depressive symptoms, aimed at searching for meaning in life through the recollection of memories (Bohlmeijer, 2007)			asking for narrative certainly contributes to eliciting future narratives, but is no guarantee for getting narrative. Consequently, why narrative future imagination sometimes occurs, and sometimes not, is a matter of analysis that has implications for health-care practice. **Recommendations:** Future research should focus on why and when participants (knowingly or not) divert from the instruction and how this is related to health and well-being
20	Duff, S. (2010). **Exploring criminogenic need through**	**Aim:** How do offending men understand themselves and	Issues of criminogenic need	The research herein examines the apology	**Rationale:** Victim apology letters, or other methods for	**Per participant:** 1 **In total:**	**Communication:** N/A **Use of self:**	**Benefits:** The current research is taking a similar approach in

	victim apology letters: An interpretative phenomenological analysis.	their behaviours in terms of criminogenic need. In order to develop programmes that successfully effect change in offenders, it is important to identify the factors that may be implicated in offending and to target these factors **Method:** Qualitative **Analysis:** Interpretative phenomenological analysis **Rationale:** as it focuses on the way in which an event is experienced by the individual who experienced it and recounts	Pre treatment apology letters of men who attended a community-based introductory sex offender treatment programme	letters of men who have offended against children and who have attended for treatment at a community forensic service. As a routine part of the introductory group treatment programme, each man is required to write two victim apology letters, one at each of two timepoints during the 16-week programme, typically at week two and at week 15. They write these letters away from the group and bring them in to be used as an exercise for group discussion. This paper focuses on the letters at the first time-point in the introductory treatment	enhancing an offending individual's empathy, have become an important component in programmes aimed at providing interventions for sexual offenders (Webster & Beech, 2000). The letters can be considered as accounts of an individual's understanding of the world, in relation to their offending and the effects of that behaviour on the victim. As such, they potentially embody important information for understanding need, a view that follows on	26 The corpus examined here consists of 26 individual letters, which include all available letters from the six most recent introductory groups, copied from the individual's treatment notes and anonymised by the service's administration staff before being passed on to the researcher	?	that it will analyse accounts that are driven by the intentions and motivations of the men who are writing them for a particular task, rather than being constrained by a semi-structured interview. **Challenges:** A second concern could be that the lack of criminogenic need might reflect either the writing ability of the men (through achieved educational level or maturation) or the age of the victim they are addressing. Without demographic information, it is not possible to address this concern directly and it is an

		it, and it seeks to explore the understandings, perceptions and views of individuals **Epistemology:** the interpretation of the data is informed by the theoretical position that the researcher has taken?		process to explore how the men, pre-treatment, conceptualise themselves, their offences and their victims	from the work of Ericsson & Simon (1980) who suggest that personal accounts are a rich source of data. As such, they require a qualitative method in order to explore the cognitive structure that an individual uses to construct their world (Benson 1985; Pogrebin et al, 1992). **Format: ?** The data consist of the first of two victim apology letters that each man writes as part of the treatment programme, typically within the first two weeks of the programme starting			important empirical question to examine **Recommendations:** ? **Other comments:** As the data were anonymised prior to analysis, each set of data from separate group therapy programmes was copied onto different coloured paper and, as such, quotes are identified by their colour (in order to provide a sense of whether themes are emerging across the different groups) and the number of the participant from that group, along with a line

					They write these letters away from the group and bring them in to be used as an exercise for group discussion **Length of time to complete: ?** **Nature of instructions:** no guidelines as to the content, length, or style of the letter so that it is a representation of how they currently understand themselves and their offending. **Length of letters:** ? **Who/what directed to:** apology letters of men who have offended against			number or line span. For example, [Green, 2, 4–7] means the extract is from the group whose letters were copied onto green paper, the second participant's letter in that group, and lines four to seven of that letter). All mistakes in the quotes are a true reflection of the original letters

					children			
21	Duff, S. (2011). **Exploring criminogenic need through victim apology letters II: an IPA analysis of post-treatment accounts of offending against children.**	**Aim:** This research aimed to explore how men based in the community, who have offended against children, conceptualise themselves, their offending and their victims, after an ISOP, and to examine if these conceptualisations pertain to criminogenic need **Method:** Qualitative **Analysis:** Interpretative phenomenological analysis (IPA) (Smith, 1996) was used because it focuses on the way in which an event is experienced by	Post treatment apology letters of men who attended a community-based introductory sex offender treatment programme	The current research focuses on post-treatment apology letters of the same group of men.	**Rationale:** Typically qualitative studies rely on the construction of semi-structured interview schedules to engage individuals, where the interview is constructed in a theory-led manner or it may be adapted through piloting or over the course of the interviews. One potential concern with this approach is that the same researcher biases that could influence the analysis of the data may also influence the ways in which the interviews are developed	**Per participant:** 1 **In total:** 26 26 individual letters, which includes all available letters from the six most recent groups.	**Communication:** N/A **Use of self:** ?	**Benefits:** ? **Challenges:** ? **Recommendations:** ?

		the individual who experienced it and recounts it, plus it aims to explore the understanding, perceptions and views of individuals (Reid et al., 2005). **Epistemology:** ?			and carried out. One approach to reduce this possibility is to allow the participants to freely write an account of the topic of interest. By employing the writing of victim apology letters the men are free to express themselves in their own language, focussing on the issues that they believe are most important in approaching this task. **Format:** The men write their letters at home and bring them to the group in order to initiate group discussion, **Length of time to complete: ?**			

					Nature of instructions: no guidelines as to the content, length, or style of the letter so that it is a representation of how they currently understand themselves and their offending. **Length of letters:** ? **Who/what directed to:** ?			
22	Webster, S. D., & Beech, A. R. (2000). **The nature of sexual offenders' affective empathy: A grounded theory analysis.**	**Aim:** To investigate the nature of sexual offenders' affective Empathy **Method:** Qualitative **Analysis:** grounded theory analysis	The nature of sexual offenders' affective empathy	Residential treatment program for child Abusers. Each participant was issued instructions to complete a victim apology letter as part of their therapeutic program.	**Rationale:** The rationale for using perpetrator statements is that by their sheer nature, victim letters not only operationalize offender affect, but also allow offenders to approach an empathic	**Per participant:** 1 **In total:** 31	**Communication:** N/A **Use of self:** ?	**Benefits:** ? **Challenges:** However, they further argue that there may be some cases in which the researcher may be cautious of taking the participants' responses at face

		Epistemology: ?			provoking arena from their own frame of reference. Furthermore, such statements offer the opportunity to examine how types of offenders (i.e., intrafamilial and extrafamilial) conceptualize an empathic response, thus providing a possible insight into the nature and extent of their specific deficits. **Format:** Participants were seated privately in a room 253 while they constructed their letters. On completion, these letters were recorded			value. Pidgeon and Henwood propose that this is due to participants not always being consciously aware of the underlying reasons behind their statements, therefore accounts may be offered to 252 perform a variety of nonobvious and context-specific functions (e.g., allocating blame to others, portraying self as victim). In short, the participants in the sample may provide data that contain an underlying agenda that subtly differs from the face value statement. **Recommendations:**

					onto a videotape. The construction of victim apology letters is a therapeutic exercise; thus, none of letters were ever sent to their intended recipients **Length of time to complete: ?** **Nature of instructions:** What I Would Like to Say to My Victim-Video Write down what you would like to say to your victim if you could. Put this on a videotape. Show the video to your group by arrangement with your therapist **Length of letters:** ?			?

					Who/what directed to: The victims of sexual abuse.			

Appendix D

Example of matrices used in SLR

Analysis

1 - ?

2 – TA

3 – TA

4 - dialogical narrative analysis (DNA) was used to analyse the written letters This form of narrative analysis focuses not only on the content of stories, but also their effects (Frank 2010). Consequently, the focus is on the relationship between the events being narrated and the event of narration, thus considering what happens as a result of telling the story. In line with Frank's, description of DNA, this form of analysis allowed us to consider how the older self looked to approve, confront, and/or modify and guide the story being told by the younger self

5 – inductive thematic analysis

6 - Content analysis

7 - We begin with a grounded-theory approach to content analysis (Strauss & Corbin, 1998), discovering thematic patterns in the letters, and aggregating those themes into a conceptual model that covers the widest possible range of responses. We then conduct a narrative analysis, reassessing each letter's narrative structure to find common patterns in the men's understanding of temporality, causality, and agency. Finally, through a comparison between the discourse and narrative analyses, we create a typology of the letters To ensure that the codes reflected the men's idiosyncratic ways of seeing the world rather than other differences in discourse practice, bivariate analyses (t test, ANOVA, chi-square) assessed the relationships between themes and demographic information

8 - Content and semantic analysis

9 - deductive content analysis and an inductive thematic analysis

10 – TA

11 - phenomenological-hermeneutic analysis

12 - ? The author analyzed the data for themes using traditional open and axial coding methods. Research poem data will be presented in the form of three types of research poems: free verse, the pantoum, and tanka

13 - reflexive thematic analysis During Phase 2 of the project, our findings were represented using what is known as a "composite first-person narrative" (Biglino et al., 2017), which is an amalgamation of our participants' voices into one story

14 - reflexive Thematic Analysis

15 - narrative analysis

16 - Whilst these letters could be analysed in many ways, the two overarching research questions for this paper are, do these letters express hope? And, if so, in what ways is this hope political? For the purposes of analysing the data, the first of these questions was divided into two sub questions (1a and 1b), and the second into four (2a, 2b, 2c, 2d). “In what ways does this letter…” 1a)…demonstrate hope? 1b)…demonstrate despair, fatalism or hopelessness? 2a)…demonstrate hope for a return to ‘normal’, or the status quo ante? 2b)…demonstrate hope for change? 2c)…indicate how the desired future will be brought about? What are the processes, mechanisms or actions? 2d)…indicate who are the ‘actors’ by whom the desired future will be achieved? We read each letter as a whole, and used Atlas.ti qualitative data analysis software to code phrases, sentences or paragraphs. The data was initially analysed with six codes, corresponding to the questions above: ‘hope’, ‘despair’, ‘return to normal’, ‘change’, ‘mechanisms’ and ‘actors’. A thematic analysis (Braun & Clarke, 2006) was then conducted within each of the six code groups, to draw out key themes. The findings from the Ecuadorean and Greek letters were then compared.

17 – TA

18 - reflexive thematic analysis - Focus group transcripts and love and break up letters were analysed together

19 - Narrative, content and comparative analysis

20 - interpretative phenomenological analysis as it focuses on the

way in which an event is experienced by the individual who experienced it and recounts

it, and it seeks to explore the understandings, perceptions and views of individuals

21 - interpretative phenomenological analysis

22 - grounded theory analysis

Timespan

1 – N/A

2 – No details provided

3 – 30 minutes

4 – No details provided

5 – N/A

6 – N/A

7 - No details provided

8 – N/A

9 – N/A

10 - No details provided

11 – No details provided

12 – N/A

13 – 20 – 30 minutes whilst in class

14 – N/A

15 - Participants could log out of the study at any time and continue writing at a later time.

16 - No details provided

17 - No details provided

18 - At the beginning of the focus group, participants were given 30 minutes to write both a love and a break up letter to empathy for patients

19 - No details provided

20 - No details provided

21 - No details provided

22 - No details provided

Instructions

1 – N/A

2 - Legacy letters (started with Cohort 10 in 2017) are written by the nurse residents completing the program in the form of a message to future nurse residents, reflecting on aspects of the experience such as“what I wish I knew” or“what I learned

3 - love and/or break-up letter to their resilience in relation to their curriculum and their experiences over the MPharm programme

4 - first provided with a prompt that encouraged them to think about a specific time point for their writing: ‘I would like you to think about a time when you would have liked to receive this letter. This could be any time that feels right for you – it could be a time when you were struggling with chronic pain, or a time when you felt like you were coping well’. The aim of this prompt was to encourage participants to visualise their younger self, moving away from a more abstract image of self to imagining the younger self at a specific point in time. Participants were then instructed: ‘Now think about what you would like this letter to say. You might consider: What advice would you like to give to yourself? What would be most helpful or comforting to hear? What would you do differently? What would you encourage yourself to keep doing the same? What would you tell yourself about the future?’ Instructions for writing the letter highlighted that participants should not be concerned with spelling, grammar or ‘getting it right’, but should construct a letter that feels right to them. Further, it was iterated that there was no ‘ideal length’ for the letter or ‘right’ way to approach this task

5 – N/A

6 – N/A

7 – The assignment asks the men to imagine a future scenario in which

they have met life goals, and to write back to themselves from that perspective

8 - Data collection was observational and non-participative: no question or query was addressed to the patients (about their reasons for writing a letter or get further information about the contents or for any other reason)

9 – N/A

10 - As a therapeutic task, group members were asked to write a letter to their partner at the beginning and end of the group, describing their feelings about his offending

11 - No details provided

12 – N/A

13 - “Older, Wiser Self Letter” Participants were provided with written guidance on letter writing (e.g., not to worry about grammar or spelling; asking questions such as “What would you like to say to your younger self?,” “What would be most helpful to hear?”

14 – N/A

15 - , the topical domain of the desired future was specified as a moment in time when the current coronavirus outbreak had ended. Second, participants were encouraged to use their imagination and focus on possibilities by asking to Remember that it is about a future which has not occurred yet. Consider it an opportunity to think about possibilities to transform your own life and the world around you for the better. Third, similar to the original instruction, the chosen time and place in which the desired future took place were not predetermined but left open for participants themselves to imagine. This openness allowed insight into the way participants themselves situate a post-pandemic future temporally and spatially. Fourth, participants were encouraged to engage in a sensory exploration of their immediate surrounding of their future world What do you see, feel, hear and smell? Then their attention was turned to the future world at large (community, society, humanity, the planet) by asking Do you notice anything about how society or nature are functioning now that the corona outbreak is over? Fifth, attention was brought to the future self with prompts such as What are you feeling, thinking, and doing? How are you dealing with opportunities and setbacks on a specific day, moment or event? Sixth, participants were asked about the pathway that led to the future just described with an openness to the agency involved in creating that future How did this future come into being, who or what has contributed to making those changes possible? And allowing for participant’s own evaluation about the pathway How do you look back on this path to the future? Finally, the participant was asked to send a message to an audience of their own choice in the present The Letter from the Future exercise was used to elicit participant’s ways of envisioning their desired post-Corona life and world. The idea is to imagine traveling to a desired future in a time machine and write a letter from that future retrospectively back to the present.

16- The brief we provided to our participants was designed to be deliberately ‘open’ in the range of post-Covid futures that could be imagined participants were invited to imagine a desirable future

17 - As a therapeutic task, group members write a letter to their partner at the beginning and end of the group, describing their feelings about his offending.

18 - Please write a love-letter to the concept of ‘empathy for patients’. Try to pretend that ‘empathy for patients’ is the entity you are in love with and tell the concept what you like and love about it and why. Try to be reflective about the points you make and link them to your own

experience. Write this love letter below. If you need more space, feel free to expand beyond this paper: Please now write a break-up letter to the concept of ‘empathy for patients’. Try to pretend that ‘empathy for patients’ is the entity you are breaking up with and tell the concept what you don’t like and might want to change about it and why. Try to be reflective about the points you make and link them to your own experience. Write this break-up letter below. If you need more space, feel free to expand beyond this paper:

19 - The two most important adaptations of the instruction were the following: (1) more emphasis on the use of narrative particulars to invoke the experienced meaning of the future self (Crites, 1986; Erikson, 2007), for example, to vividly imagine a particular situation at a particular moment in the future in which something positive has been realized and (2) leaving the particular audience to whom the letter had to be addressed open to choice (originally the audience was the group of other participants in the reminiscence course).

20 - no guidelines as to the content, length, or style of the letter so that it is a representation of how they currently understand themselves and their offending

21 - no guidelines as to the content, length, or style of the letter so that it is a representation of how they currently understand themselves and their offending.

22 – What I Would Like to Say to My Victim-Video Write down what you would like to say to your victim if you could. Put this on a videotape. Show the video to your group by arrangement with your therapist

Appendix E

CASP Appraisal Tool

CASP checklist questions	**1) Was there a clear statement of the aims of the research?**	**2) Is a qualitative methodology appropriate?**	**3) Was the research design appropriate to address the aims of the research?**	**4) Was the recruitment strategy appropriate to the aims of the research?**	**5) Was the data collected in a way that addressed the research issue?**	**6) Has the relationship between the researcher and participants been adequately considered?**	**7) Have ethical issues been taken into consideration?**	**8) Was the data analysis sufficiently rigorous?**	**9) Is there a clear statement of findings?**	**10) How valuable is the research?**
(1) Cummings, C. & Gruenert, S. (2011).	Yes	Yes	Yes	Yes	Yes	No (the researcher did not share their own role or potential biases during formulation of the research question or data	Can't tell (researcher did not discuss issues around consent or confidentiality or if approval was sought from ethics committee)	Can't tell (not an in depth description of analysis process, no contradictory data taken in to account, sufficient data not presented,	No (not an adequate discussion, no discussion of credibility of findings, findings aren't discussed in relation to original	The researcher did not discuss the contribution to existing knowledge or understanding, they di not identify other new areas for

						collection, or how they responded to events during the study)		researcher didn't critically examine their role)	research questions)	research, they did not discuss how research could be transferred ro where research can be use)
(2) Brown, J., Fowler, S., & Mason, T. M. (2023).	Yes	Yes	Yes	Yes	Yes	No (the researcher did not share their own role or potential biases, or how they responded to events during the study)	Can't tell , ethical approval was described but o further details discussed	Yes, could explore contradictor y findings	Yes	The researcher did discuss the contribution s this study makes and identified a new area of research, but they did not discuss how the findings can be transferred to other populations or consider other ways the findings

										could be used.
(3) Mawdsley, A., & Willis, S. C. (2023).	Yes	Yes	Cant tell – multi method, 2 types qual data collected no in depth rationale as to why	Yes	Yes	No (the researcher did not share their own role or potential biases, or how they responded to events during the study)	Can't tell , ethical approval was described but no further details discussed.	Yes, could explore contradictory findings	Yes	The researcher did discuss the contributions this study makes and identified a new area of research, they discussed a limitation of the study is the transferability due to small sample and one site, they did not discuss other ways the findings could be used.
(4)	Yes	Yes	Yes	Yes	Yes	Can't tell, the	Yes, ethical approval	Yes	Yes	The researcher

Day, M. C., Hine, J., Wadey, R., & Cavalleri o, F. (2023).						researcher does describe how they responded to some events in the study, but their own role and potential biases were not discussed	noted, and some discussion around response to letters and care of participants, could have detailed more such as consent and confidentiali ty			did discuss the contribution s this study makes and identified a new areas of research, but they did not discuss how the findings can be transferred to other populations .
(5) Burry, K., Beek, K., Worth, H., Vallely, L., & Haire, B. (2023).	Yes	Yes	Yes Our analysis included news articles, editorials, opinion pieces, and letters to the editor.	Yes	Yes	Cant tell, the researcher describes that they are cultural outsiders, but does not share how this may bias, or how they responded	Cant tell, no details provided	Cant tell, limited information on steps of analysis, researcher does not critically examine their own role,	Cant tell, findings are made explicit but no discussion against arguments , no discussion of credibility, findings	The researcher does discuss contribution to existing knowledge, they do not identify new areas of research, they do not state how

			News articles report facts and informati on on a topic and should appear unbiased and objective, presentin g a range of views while not promotin g any particular stances or opinions on the topic.46 Editorials, opinion pieces, and letters to the editor, however,			to events in the study			are discussed in relation to original research question	findings can be transferred or ways the research might be used

			build arguments and promote the opinions of an institution or media outlet (as in editorials), or of an individual (as in opinion pieces and letters to the editor) on a particular topic.46,47 While we expected editorials, opinion pieces, and							

			letters to the editor to build arguments and promote viewpoints on abortion, we have included news articles to analyse whether or how bias appears in apparently value-neutral texts on abortion in Pacific Island media outlets							

(7) Kilgore, C. D., Lehmann, P., & Voth Schrag, R. (2019).	Yes	Yes	Yes	Yes	Yes	No (the researcher did not share their own role or potential biases, or how they responded to events during the study)	Cant tell, no details provided	Cant tell, limited description of analysis process. Researcher did not critically examine oen role, contradcitory data not taken in to account	Cant tell, no discussion against findings, but findings are explicit, they did deicsuss credibility, fidnigns are discussed in relation question	The researcher does discuss contribution to existing knowledge, they do identify new areas of research, they do not state how findings can be transferred or ways the research might be used
(8) Perrot, S., Launay, A., Desjeux, D., & Cedraschi, C. (2017).	Cent tell, the aims could have been made clearer	Yes	Yes	Yes	Yes	No (the researcher did not share their own role or potential biases, or how they responded to events	Yes	Cant tell, could have shared more information on process of analysis, and contradictory data, and	No, findings could be more explicit, discussion needed against findings, findings in	The researcher did discuss the contribution this study makes, they did make a suggestion for further

						during the study		own role and biases	relation or original question could have been clearer, credibility of findings not discussed	research, , they did not discuss how findings could be transferred to other populations or other ways the research could be used
(9) Jensen, L. (2014).	Yes	Yes	Yes	Yes	Yes	No (the researcher did not share their own role or potential biases, or how they responded to events during the study	Cant tell, no details provided	Cant tell, could have been fuller description of analysis process, did not mention contradictory findings, did not examine their own role	Cant tell, The findings are explicit, no discussion of evidence against arguments, no discussion of credibility,	The researcher did discuss the contribution this study makes, they did not make a suggestion for further research, , they did not discuss how findings could be transferred

										to other populations or other ways the research could be used
(10) Cahalane, H., Parker, G., & Duff, S. (2013).	Yes	Yes	Yes	Yes	yes	No (the researcher did not share their own role or potential biases, or how they responded to events during the study	Yes	Cant tell, description of analysis process but did not mention contradictory findings, did not examine their own role	Yes	The researcher does discuss the contribution this study makes and identity news areas of research, the did not discuss how findings could be transferred
(11) Zannini, L., Cattaneo, C., Brugnolli, A., &	Yes	Yes	Yes	Yes	Yes	Cant tell Researcher did not share how they responded to events	Yes	Cant tell Contradictory data not discussed Although preconcepti	Cant tell No contradictory arguments	They did discuss the contribution the study made Did not discuss

Saiani, L. (2011).						during the study. They did share about that during analysis researcher did share their preconcepti ons and that they kept a reflexive attitude but no further details included		ons and self reflexivity were mentioned they were not explored.		future research possibilities They did discuss how fidnings an be transferred or future considered
(12) Furman, R., & Shukraft, A. (2007).	Yes	Yes	Yes	Yes	Yes	No (the researcher did not share their own role or potential biases, or how they responded to events during the study	No Ethical approval or exploration of ethical issues were not noted	Cant tell Analsis could have been more detailed, conyradictor y findings not mentioned, researcher did not	No Findings are not explicit, not adequate discussion for or against results, they did	Rsearcher does not discuss contribution of study, they identify how research poems could be used but not further

								critically examine own role	not discuss credibility fo their findings, findings not discussed in relation to original research question	research in the topic area, they have not discussed how fidngs could be transferred to other populations .
(13) Timmis, M. A., Pexton, S., & Cavalleri o, F. (2022)	Yes	Yes	Yes	Yes	Yes	Cant tell The researcher states briefly their positionality, but no further reflections, and does not share how they responded to events in the study	Cant tell Ethical approval was noted, but not further ethics details noted.	Yes, but could explore contradictor y findings, and their own role in analysis	Cant tell No discussion of evidence against	Researcher does discuss the contribution made, and identify a new area for researcher, but they do not discuss how the findings can be transferred
(14)	Yes	Yes	Yes	Yes	Yes	No (the researcher	No mention of ethical	Cant tell,	Cant tell,	Researcher does

Abnett, H. (2023).						did not share their own role or potential biases, or how they responded to events during the study	approval or further details	Analysis described, but not clear how it was applied or findings were developed from this, contradictory data not taken in to account, researcher doesn't critically examine own role	Findings are explicit, but no evidence against researcher arguments, researcher does not discuss credibility	discuss the contribution, they have identified further research, they do discuss how this could be applied to other populations
(16) Gross, J., Davids, T., Sools, A., & Saghai, Y. (2023).	Yes	Yes	yes	yes	yes	No (the researcher did not share their own role or potential biases, or how they responded to events during the study	No, ethical approval and ethical issues not noted	Yes, but researcher does not examine own role	Cant tell, No evidence against researcher arguments, no discussion of credibility	The resesrcher does discuss the contribution made, they identody new areas fo research, and other ways the research

										could be used, but not transferred.
(17) Cahalane, H., & Duff, S. (2018).	Yes	Yes	Yes	Yes	Yes	No (the researcher did not share their own role or potential biases, or how they responded to events during the study	Yes	Yes, but could explore contradictory findings, and their own role in analysis and their own role	Yes	The research does discuss the contribution to existing knowledge, they identify new areas of research, they don't discuss how the findings could be transferred to other populations
(18) Laughey WF, Brown MEL, Dueñas AN, et al. (2021).	Yes	Yes	Cant tell – multi method, 2 types qual data collected no in depth	Yes	Yes	Cant tell, The researcher did not share their own role and potential biases or	Cant tell, Ethical approval was sought, no further discussion around ethics	Yes, but could explore contradictory findings, and their own role in analysis and	Cant tell Research does not discuss arguments against	The researcher does discuss contribution to existing knowledge, they have identified

			rationale as to why			how they responded to events during the study		their own role The researcher shared they identified their personal reflections on empathy, but no further discussions on potential bias or influence or how they responses to events during the study		further research, the researcher did not discuss how findings could be transferred
(19) Sools, A. M., Tromp, T., & Mooren, J. H. (2015).	Yes	Yes	Yes	Yes	Yes	No (the researcher did not share their own role or potential biases, or how they	No, no mention of ethical approval or consideratio ns	Yes, but could explore contradictor y findings, and their own role in analysis and	Cant tell Research does not discuss arguments against or credibility	The researcher does discuss the contribution , , they do identify a new area of

						responded to events during the study		their own role		research, they don't discuss how findings can be transferred to other populations or other ways the research could be used
(20) Duff, S. (2010).	Yes	Yes	Yes	Yes	Yes	No no discussion around how the researcher responded to the events in the study. researcher did not share their own role or potential bias	Cant tell, mentions ethical approval sought but no other details	Yes, but did not explore their own role potential biases. A mention that the analysis would fall in line with theoretical position but no further discussion,	Yes, but did not discuss credibility	The researcher does discuss the contribution, they do identify new areas of research, they do not discuss how findings can be transferred to other populations

(21) Duff, S. (2011).	Yes	Yes	Yes	Yes	Yes	Cant tell, Does not share own role, researcher does not describe how they responded to events	Yes	Yes, but researcher does not critically examine own role Inter rater reliability was not used, but discussions had in team, no further details,	Yes but, Does no describe credibility,	The researcher does describe the contribution, they identify new areas, but they do not describe how findings van be transferred.
(22) Webster, S. D., & Beech, A. R. (2000).	Yes	Yes	Yes	Yes	Yes	No (the researcher did not share their own role or potential biases, or how they responded to events during the study	No, no mention of ethical approval or consideratio ns	Cant tell Contradictor y data not taken in to account, researcher doesn't critically examine own role	Yes	The researcher does describe the contribution, they identify new areas, but they do not describe how findings van be transferred.

Appendix F

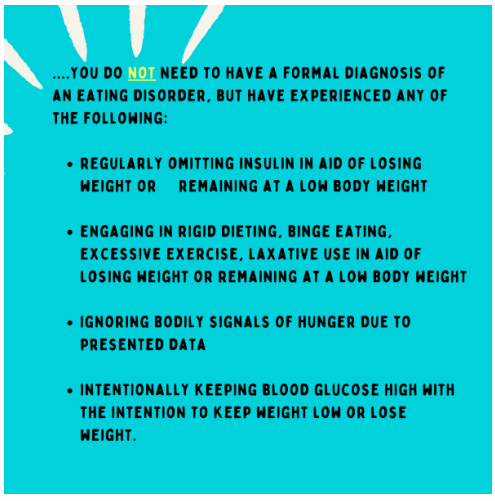
MMAT appraisal tool

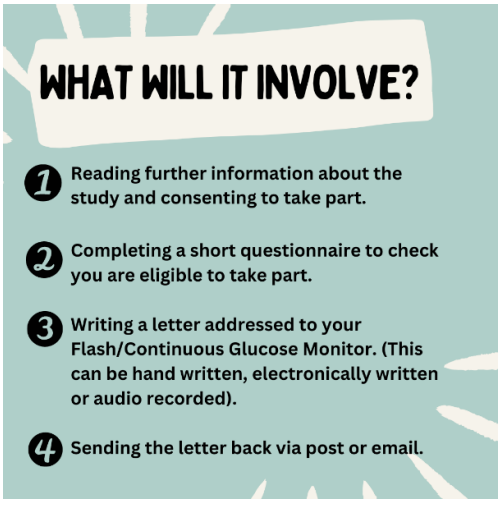
	Methodological quality criteria	Yes	No	Can't tell	Comments
(6) Schmitz, H. P., Mitchell, G. E., & McCollim, E. M. (2021).	1. Are there clear research questions?	*Yes*			
	2. Do the collected data allow to address the research questions?	*Yes*			
	3. Is there an adequate rationale for using a mixed methods design to address the research question?			*Can't tell*	*Could be clearer.*
	4. Are the different components of the study effectively integrated to answer the research question?			*Can't tell*	*Each analysis is described but not sure how integrated*
	5. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?			*Can't tell*	*It seems each part are interpreted but not sure how they come together*
	6. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?		*No*		*Not discussed*
	7. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	*Yes*			
(15) Hänninen, V., & Sools, A. (2022).	1. Are there clear research questions?	Yes			
	2. Do the collected data allow to address the research questions?	Yes			
	3. Is there an adequate rationale for using a mixed methods design to address the research question?			Can't tell	*Rationale not explicit*
	4. Are the different components of the study effectively integrated to answer the research question?	No			*No mention of results from survey in main body of text only in supplemental information, not integrated*
	5. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	No			
	6. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	No			
	7. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	No			*Survey not reported on*

Appendix G

Study Adverts

(Supervisor and researcher contact details removed for appendix)





PARTICIPANTS WANTED!

TYPE 1 DIABETES, DISORDERED EATING AND DIABETES TECHNOLOGY RESEARCH

This research aims to get a better understanding of what relationship people with type 1 diabetes and disordered eating have with their Flash/Continuous Glucose Monitors.

WE ARE LOOKING FOR PARTICIPANTS WHO ARE...

- AGED 18 AND OVER
- LIVE IN THE UK
- HAVE TYPE 1 DIABETES
- CURRENTLY USE A FLASH/CONTINUOUS GLUCOSE MONITOR (AND HAVE DONE FOR AT LEAST 12 MONTHS)
- EXPERIENCE **CURRENT OR PREVIOUS** DISORDERED EATING / DIABULIMIA. THIS MEANS....

....YOU DO **NOT** NEED TO HAVE A A DIAGNOSIS OF AN EATING DISORDER, BUT HAVE EXPERIENCED ANY OF THE FOLLOWING:

- regularly omitting insulin in aid of losing weight or remaining at a low body weight
- engaging in rigid dieting, binge eating, excessive exercise, laxative use in aid of losing weight or remaining at a low body weight
- Ignoring bodily signals of hunger due to presented data
- intentionally keeping blood glucose high with the intention to keep weight low or lose weight.

WHAT WILL IT INVOLVE?

1. Reading further information about the study and consenting to take part
2. Completing a short questionnaire to check you are eligible to take part.
3. Writing a letter addressed to your Flash/Continuous Glucose Monitor. (This can be hand written, electronically written or audio recorded).
4. Sending the letter back via post or email

FOR FURTHER INFORMATION, AND TO COMPLETE THE QUESTIONNAIRE TO REGISTER YOUR INTEREST FOLLOW THE LINK IN BIO OR EMAIL:

This study was ethically approved by the University of Hertfordshire HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA . Protocol number: LMS/PGR/UH/05465

Appendix H

General instructions for letter-writing task.

Letter instructions return via email

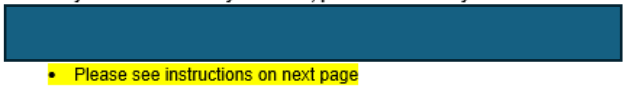
Letter writing instructions.

A note before getting started…
If you find that this activity brings up distress related to your diabetes and disordered eating, you may wish to take a break from the activity and come back to it at another time or alternatively seek some support.
The professional code of contact means that I (Emily Williams) cannot individually support participants in the study, which is why we have created the list below should you require further support.
If you feel that your participation has highlighted particular physical or mental health difficulties that you would like support with, please get in touch with the below organisations.

- Your GP
- Your diabetes service
- Diabetes UK https://www.diabetes.org.uk/
  Helpline: 0345 123 2399, Monday to Friday 9am to 6pm
- BEAT eating disorder https://www.beateatingdisorders.org.uk/
  Helpline open 365 days a year from 9am – midnight during the week, and 4pm–midnight on weekends and bank holidays. tel:0808 801 0677
- If you are in need of urgent help, please contact 999 or the Samaritans on 116 123 if you or someone else is in immediate danger.

- Thank you for taking part in this study. You are being asked to write a letter addressed to your Flash/Continuous Glucose Monitor.
- You don't need to worry about spelling, grammar or 'getting it right,' but should construct a letter that feels right for you.
- There is no ideal length for this letter, but we would encourage you to write enough to provide a rich understanding of your experience. You may choose to write it in one sitting or come back to it on a few occasions.
- We would encourage you to write you letter when you are in a private space.

When you have finished your letter, please return it by the date indicated in the



- Please see instructions on next page

We would like to know about the relationship you have with your Flash/Continuous Glucose Monitor. You may want to include life before the monitor, how/if the monitor has had an impact, and what you would like from your relationship to it in the future. These are just some ideas, and there is no right or wrong way to write the letter. Please start your letter below.

Dear Flash/Continuous Glucose Monitor….

Postal instructions.

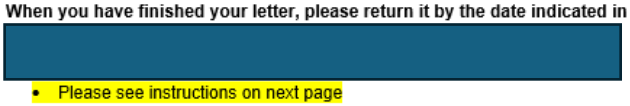
Letter writing instructions.

A note before getting started...
If you find that this activity brings up distress related to your diabetes and disordered eating, you may wish to take a break from the activity and come back to it at another time or alternatively seek some support.
The professional code of contact means that I (Emily Williams) cannot individually support participants in the study, which is why we have created the list below should you require further support.
If you feel that your participation has highlighted particular physical or mental health difficulties that you would like support with, please get in touch with the below organisations.

- Your GP
- Your diabetes service
- Diabetes UK https://www.diabetes.org.uk/
  Helpline: 0345 123 2399, Monday to Friday 9am to 6pm
- BEAT eating disorder https://www.beateatingdisorders.org.uk/
  Helpline open 365 days a year from 9am – midnight during the week, and 4pm–midnight on weekends and bank holidays. tel:0808 801 0677
- If you are in need of urgent help, please contact 999 or the Samaritans on 116 123 if you or someone else is in immediate danger.

- Thank you for taking part in this study. You are being asked to write a letter addressed to your Flash/Continuous Glucose Monitor.
- You don't need to worry about spelling, grammar or 'getting it right,' but should construct a letter that feels right for you.
- There is no ideal length for this letter, but we would encourage you to write enough to provide a rich understanding of your experience. You may choose to write it in one sitting or come back to it on a few occasions.
- We would encourage you to write you letter when you are in a private space.

When you have finished your letter, please return it by the date indicated in the



- Please see instructions on next page

We would like to know about the relationship you have with your Flash/Continuous Glucose Monitor. You may want to include life before the monitor, how/if the monitor has had an impact, and what you would like from your relationship to it in the future. These are just some ideas, and there is no right or wrong way to write the letter. Please start your letter below.

Dear Flash/Continuous Glucose Monitor….

Appendix I

Study Information, consent and demographic questionnaire

Thank you for clicking the link to register your interest in taking part in this study.

This form is to register interest to take part in the study, 'If only my glucose monitor knew.' A study of letters written to flash and continuous glucose monitors by those living with Type 1 Diabetes and disordered eating.

You will be asked to read some information about the study, consent to taking part, and answer some initial screening questions.

If you are eligible for the study, you will later be sent the instructions to complete the research task, at time that suits you.

If you are not eligible to take part in the study, you will be emailed or written to to let you know.

Study information

You have been invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include.

Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

What is the title of the study?

'If only my glucose monitor knew.' A study of letters written to flash and continuous glucose monitors by those who living with Type 1 Diabetes and disordered eating.

What is the purpose of this study?

This research aims to get a better understanding of what relationship and experience people with type 1 diabetes and eating disorders have with their Flash Glucose Monitor/Continuous Glucose Monitor (FGM/CGM).

Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be asked to indicate your consent later in this form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason.

Are there any age or other restrictions that may prevent me from participating?

Participants must be living in the UK and be 18 years or older to take part. Participants must be

- living with Type 1 diabetes
- identify has currently or previously experiencing disordered eating/diabulimia*,
- and use a flash/continuous glucose monitor for at least 12 months.

* This means any of the following:

- regularly omitting insulin in aid of losing weight or remaining at a low body weight

- engaging in rigid dieting, binge eating, excessive exercise, laxative use in aid of losing weight or remaining at a low body weight

- intentionally keeping blood glucose high with the intention to keep weight low or lose weight.

What will happen to me if I take part?

The first thing to happen will be that you are asked a few screening questions below, to ensure that you are eligible to take part in the study.

One this is submitted; you will be sent an email or letter in the post (depending on your preference) with instructions to write a letter addressed to your FGM/CGM. Please note that not everyone will be invited to participate as a limited number of people are required and we seek a diverse sample of participants. (Or you will be notified that you are unfortunately not eligible to take part in the study).

Instructions will be: We would like to know about the relationship you have with your Flash/Continuous Glucose Monitor. You may want to include life before the monitor, how/if the monitor has had an impact, and what you would like from your relationship to it in the future. These are just some ideas, and there is no right or wrong way to write the letter.

Alongside the instructions you will also be sent information on avenues for support if you find that the letter writing highlights any difficulties you have been experiencing.

You will be given 4 weeks to write your letter. You will be prompted once at the end of this time frame with a reminder to complete and send your letter if I haven’t heard back from you. If you have changed your mind, I won’t email you again.

You will be asked to send this letter back via email or in the post with the provided stamped addressed envelope. (If you would prefer to access this study by audio recording your letter and sending it via email you can select this option).

You will be emailed informing you that we have received your letter.

Once you have submitted your letter you will be asked if you wish to be entered into a prize draw for love 2 shop vouchers, there will be a first prize of £40 and second prize of £20. You can still enter the prize draw if you submit a letter and later decided to withdraw it within the two-week time frame). Once all participants have completed the study, you will be emailed if you have won. If you win you will be asked to sign a pay agreement, which will be stored on the secure UH one drive until completion of the project. The vouchers will be sent via email and can be redeemed through a link.

You can withdraw your letter from the study for up to two weeks after you have submitted it by emailing xxxxx, if you decide you no longer want it to be included in the research.

If you opt to receive it, you will also be sent a small summary of the results of the study.

How long will my part in the study take?

The length of time this study takes will depend on how long you choose to spend on writing the letter, this could for example take as little as 30 minutes or you may choose to come back to writing it on a number of occasions.

What are the possible disadvantages, risks or side effects of taking part?

You may find that the writing task encourages you to think about difficulties you have had or may be experiencing in relation to your diabetes, diabetes technology and disordered eating.

It will be your responsibility to take care of yourself and stop if you feel distressed and only come back to it when you are ready. If you find writing your letter to be too upsetting, please leave it and follow avenues of support provided if needed.

What are the possible benefits of taking part?

Possible benefits of taking part could be that the research highlights personal achievements and benefits of your healthcare. You will also help to contribute to broaden the understanding of people's relationship and experiences of using a FGM/CGM when they have Type 1 diabetes and disordered eating. By exploring this relationship, we hope that findings could offer recommendations that could be implemented in clinical practice to better support patients with Type 1 diabetes and disordered eating who use a FGM/CGM.

By taking part in the letter writing task you may also may also better understand and gain insights in to the relationship you have to your diabetes technology.

Some describe letter writing as a therapeutic and stress reducing.

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

Your demographic information and contact details provided in the initial screening questionnaire will be submitted through Qualtrics an online secure platform, this will be kept separate from your letter.

You are encouraged to write the letter in a private place.

What will happen to the letter I submit?

Letters will be emailed to a password protected two factor authenticated University of Hertfordshire email address, then will be stored electronically in a two factor authenticated password protected University of Hertfordshire OneDrive.

Letters that are posted will be kept digitalised when received, and the originals shredded.

Anonymised letters will be securely kept for future studies for up to 5 years, at which time it will be deleted.

The letters will be analysed using a qualitative methodology exploring important themes that are discussed.

Anonymised quotes from the letters may be used in the write up of the study and when sharing the findings.

Once you have written and sent your letter you will be asked whether you are happy for the letter (once fully anonymised e.g taking out any identifiable information) to be shared as a whole piece as a teaching tool, and a tool to raise awareness. **You do not have to consent to this to take part in the study.**

Will the data be required for use in further studies?

The data collected may be re-used or subjected to further analysis as part of a future ethically-approved study; the data to be re-used will be anonymised.

Who has reviewed this study?

This study has been reviewed by:

- The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

The UH protocol number is <*enter*>

Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me by email:

xxx

xxx

Supervisor

xxx

xxx

xxx

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

Consent

Thank you very much for reading this information and giving consideration to taking part in this study. Now that you have read this information you will be asked to indicate you consent to taking part and provide initial screening information.

Please consider each statement below carefully. By ticking the consent box below, you are consenting to taking part in the study, and if eligible will be sent instructions for the letter writing task.

……..

- I confirm that I understand the purpose of the research and what participation will involve.
- I understand that my participation is voluntary and that I am free to withdraw from the study before I begin the letter or during the letter writing task without giving a reason. I can withdraw my letter for up to two weeks after it has been submitted.
- I am aware that I will be contacted with the letter writing instructions, once with a reminder to complete the letter, and on receipt of the letter.
- I understand how the screening information I provide will be stored on Qualtrics a secure online platform which will be deleted on completion of the study.
- I understand that the letter will be stored on a secure University OneDrive that only the research team will have access.
- I am aware that the information I provide will be used for the purposes of the research, unless I decide to withdraw at any point during the study.
- I understand that my letter will be stored until the completion of this project and up to 5 years for potential similar projects of research.

- I am aware that the anonymised information I provide, for example quotes from my letter, may be used and presented in publications or presentations in academic and healthcare settings.
- I am aware that after I have submitted my letter I will be asked if I would be happy for my full letter to be shared (once fully anonymised of any identifiable information) for teaching and awareness purposes. **I am aware that I do not have to consent to this, and this will not impact taking part in the study.**
- I have been provided with the contact details of the researcher if I have any questions.

……

If there are any issues above that you do not understand, please ask for clarification before continuing.

By consenting below, if you are eligible, you will be sent the letter writing task instructions.

Please tick to consent to taking part in this study ☐

Screening questionnaire

To ensure that we are recruiting participants who meet the criteria for the study, we would like to ask you a few questions.

Age:

Gender:

Ethnicity:

Are you UK based? **Y/N**

If yes which City/Town?

Do you have Type 1 diabetes? **Y/N**

How long have you had Type 1 diabetes for?

Do you use a Flash Glucose Monitor/Continuous Glucose Monitor? **Y/N**

Flash

Continuous

Have you used a Flash Glucose Monitor/Continuous Glucose Monitor for at least 12 months? **Y/N**

Would you consider yourself to have currently or previously experienced disordered eating/diabulimia/T1DE? This could include:

- regularly omitting insulin in aid of losing weight or remaining at a low body weight

  and/or

- engaging in rigid dieting, binge eating, excessive exercise, laxative use in aid of losing weight or remaining at a low body weight

  and/or

- intentionally keeping blood glucose high with the intention to keep weight low or lose weight.

Tick the appropriate

Currently experience:

Previously experienced:

Other:

How would you like to submit your letter (please tick)

1. Word document via email
2. Handwritten and posted
3. Audio recorded and sent via email

Please provide your contact details so that the researcher can inform you about your eligibility to take part, and contact you with the letter writing instructions.

Please provide your email address.

If you would like to send your letter in the post please also provide your home address.

……

Appendix J

Ethics approval

University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	**Emily Williams**
CC	**Dr Jen Heath**
FROM	**Dr Rebecca Knight PhD, Health, Science, Engineering and Technology ECDA Vice Chair**
DATE	**05/10/2023**

Protocol number: LMS/PGR/UH/05465

Title of study: 'If only my glucose monitor knew.' A study of letters written to flash and continuous glucose monitors by those who living with co-occurring Type 1 Diabetes and disordered eating.

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:

Members of the UH DClinpsy advanced research methods thematic analysis workshop may be shown anonymised data to support analysis and the development of themes

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: 05/10/2023

To: 30/09/2024

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.
Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit form EC2.
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.
Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix K

Ethical amendment 1

University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Emily Williams
CC	Dr Jennifer Heath
FROM	Dr Rebecca Knight, Health, Science, Engineering and Technology ECDA Vice-Chair
DATE	14/12/2023

Protocol number: **aLMS/PGR/UH/05465(1)**

Title of study: 'If only my glucose monitor knew.' A study of letters written to flash and continuous glucose monitors by those who living with Type 1 Diabetes and disordered eating.

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Members of the UH DClinpsy advanced research methods thematic analysis workshop may be shown anonymised data to support analysis and the development of themes.

Modification:

Additional question added to the registration form as detailed in the approved EC2 application.

General conditions of approval:

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

Original protocol: Any conditions relating to the original protocol approval remain and must be complied with.

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: 14/12/2023

To: 30/09/2024

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.
Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit a further EC2 request.
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A or as detailed in the EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.
Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix L

Ethical amendment 2

University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Emily Williams
CC	Dr Jennifer Heath
FROM	Dr Rebecca Knight; Health, Science, Engineering and Technology ECDA Vice-Chair
DATE	25/01/2024

Protocol number:	**aLMS/PGR/UH/05465(2)**
Title of study:	'If only my glucose monitor knew.' A study of letters written to flash and continuous glucose monitors by those who living with Type 1 Diabetes and disordered eating.

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

No additional workers named.

Modification:

Change from one reminder to take part in the study to two reminders. The wording will change in the information sheet as detailed in the approved EC2 application.

General conditions of approval:

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

Original protocol: Any conditions relating to the original protocol approval remain and must be complied with.

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: 25/01/2024

To: 30/09/2024

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.
Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit a further EC2 request.
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A or as detailed in the EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.
Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix M

Contacts for further support

A note before getting started…

If you find that this activity brings up distress related to your diabetes and disordered eating, you may wish to take a break from the activity and come back to it at another time or alternatively seek some support.

The professional code of contact means that I (Emily Williams) cannot individually support participants in the study, which is why we have created the list below should you require further support.

If you feel that your participation has highlighted particular physical or mental health difficulties that you would like support with, please get in touch with the below organisations.

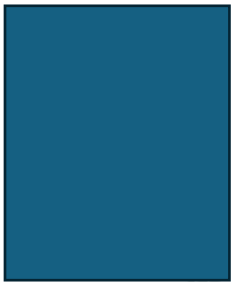
- Your GP
- Your diabetes service
- Diabetes UK https://www.diabetes.org.uk/

  Helpline: 0345 123 2399, Monday to Friday 9am to 6pm
- BEAT eating disorder https://www.beateatingdisorders.org.uk/

Appendix N

Debrief

Contact details



Thank you for your participation in our study! Your participation is greatly appreciated.

This letter may have taken you much time, and may have been an emotive experience for you, so thank you again for taking part.

What is the purpose of this study?

This study aims to explore the relationship that those who have co-occurring Type 1 diabetes and eating disorders/disordered eating behaviours relationship to their diabetes technology: FGM/CGM. By exploring this relationship, we hope that findings could offer recommendations that could be implemented in clinical practice to better support patients with Type 1 diabetes and disordered eating who use a FGM/CGM.

What if I was impacted by the study?

This study was asking about people's experience of diabetes technology in a difficult context of diabetes and eating difficulties. Writing about diabetes and eating disorder difficulties may bring up distress related to these difficulties. You may therefore find it helpful to contact one of the organisations you were notified of before beginning your letter. Please see these contact details again below for reference.

The professional code of contact means that I (Emily Williams) cannot individually support participants in the study, which is why we have created the list below should you require further support.

If you feel that your participation has highlighted particular physical or mental health difficulties that you would like support with, please get in touch with the below organisations.

- Your GP
- Your diabetes service
- Diabetes UK https://www.diabetes.org.uk/

Helpline: 03451232399, Monday to Friday 9am to 6pm

- BEAT eating disorder https://www.beateatingdisorders.org.uk/
  Helpline open 365 days a year from 9am – midnight during the week, and 4pm–midnight on weekends and bank holidays. tel:0808 801 0677

- If you are in need of urgent help, please contact 999 or the Samaritans on 116 123 if you or someone else is in immediate danger.

Please could you let us know the following:

1. **Would you like to be sent the results of the study? Y/N**

2. **Would you like to be entered into a prize draw to win love 2 shop vouchers for taking part in the study. First prize £40 love 2 shop voucher, second prize £20 love to shop voucher. You can enter the prize draw if you submit a letter and later decided to withdraw the letter from the study (you can withdraw your letter up to two weeks after submission). If you opt to take part you will be emailed with results of the prize draw once everyone has taken part in the study.**

   Y/N

3. **Would you be happy for your full letter to be shared (once fully anonymised of any identifiable information) for teaching and awareness purposes? Y/N**

Thank you again for your participation, I look forward to hearing from you.

Appendix O

Distress protocol

Participant raises concerns regarding disordered eating or diabetes management practices in letter	Send contacts for further support on receiving letter.			
Participants contact researcher outside of expected communication raising concerns about disordered eating or diabetes management practices	Acknowledge the email, reiterate remits of researcher role, send contacts for further support.			

Appendix P

Pay agreement

AGREEMENT FOR VOLUNTEERS & LAY MEMBERS INVOLVEMENT IN RESEARCH

Doctorate in Clinical Psychology research study:

Title: A study of letters written to flash and continuous glucose monitors by those living with Type 1 diabetes and disordered eating

---

This research project is a study based at the University of Hertfordshire [or for NHS studies: XXXX Trust and the University of Hertfordshire]. The researcher is Emily Williams . The purpose of the study is to understand the relation those with type 1 diabetes and disordered eating have with their diabetes tech (flash and continuous glucose monitors.

Payment will be made to volunteers and lay members of the public for their participation in meetings and other research involvement activities. The project will finish on 13/09/2024.

This form must be completed by the participating volunteer before payment can be made. Any queries concerning this Agreement should be referred to the relevant Head of Research Centre at the University of Hertfordshire

Between: **The University of Hertfordshire**

and

(The "Participating Volunteer")

ACTIVITY Volunteer for Doctorate in Clinical Psychology research study

The **Participating Volunteer** has agreed to assist the University by voluntarily taking part in the research **Activity**.

1. The Activity to be undertaken is described below and it is the Activity for which you have given your consent/agreement.

Review participant information and materials as a Participating Volunteer Give his/her views to inform the research process and direction. There will be no requirement for the participating volunteer to attend all meetings or take part in all activities.

CONFIRMATION OF ATTENDANCE

2. The Researcher will confirm the Participating Volunteer has attended the Activity outlined above.

PAYMENT

3. The Participating Volunteer will receive a participation payment of £20ph in the form of vouchers for completion of the activities described above. Payment will not be made for any activities in which the Participant did not participate at all.

RELATIONSHIP BETWEEN THE UNIVERSITY AND THE PARTICIPATING VOLUNTEER

4. **The University does not regard the Participating Volunteer as an employee of the University nor as a worker, and the payment made to the Participating Volunteer for the participation is not made with respect to any employment relationship with the University.**
5. **The Participating Volunteer is advised that it is their personal responsibility to declare any payment for participation to HM Revenue & Customs under Self-Assessment, if that is appropriate to their personal circumstances. The University will not deduct income taxes from the payment.**

SIGNED FOR AND ON BEHALF OF THE UNIVERSITY

The signatory for the University confirms they have authority to enter into this agreement on behalf of the University e.g., Principal Investigator

SIGNED .....

PRINT NAME .....

Position at UH .....

DATE .....

SIGNED BY THE PARTICIPATING VOLUNTEER

I acknowledge receipt of a copy of this agreement and accept its terms.

SIGNED .....

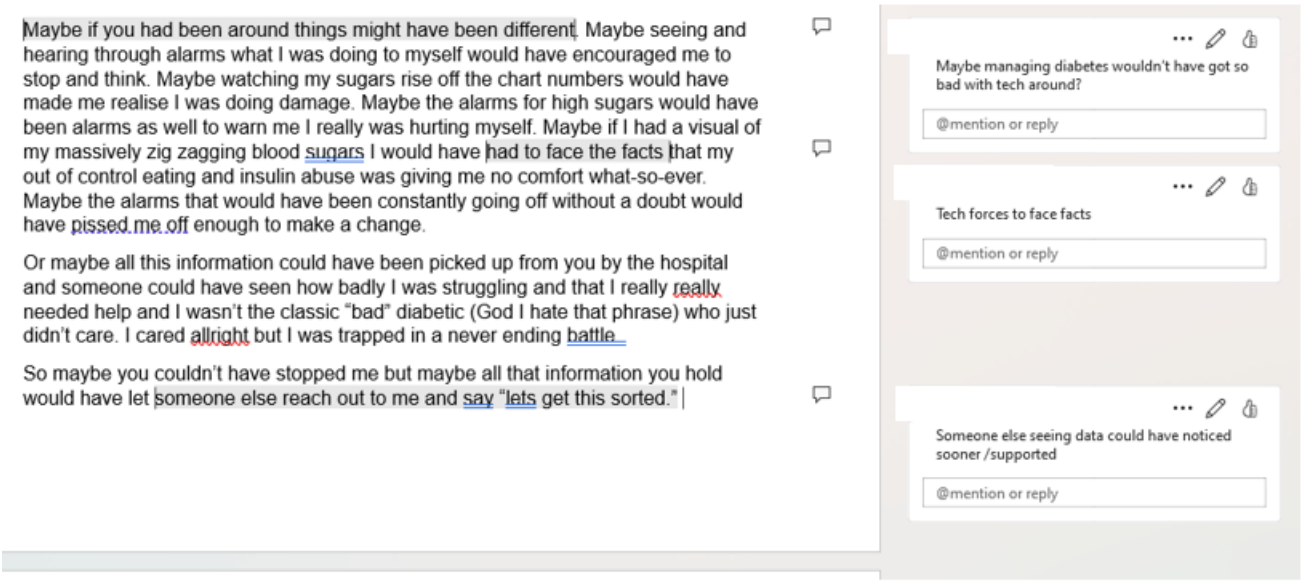
PRINT NAME .....

DATE .....

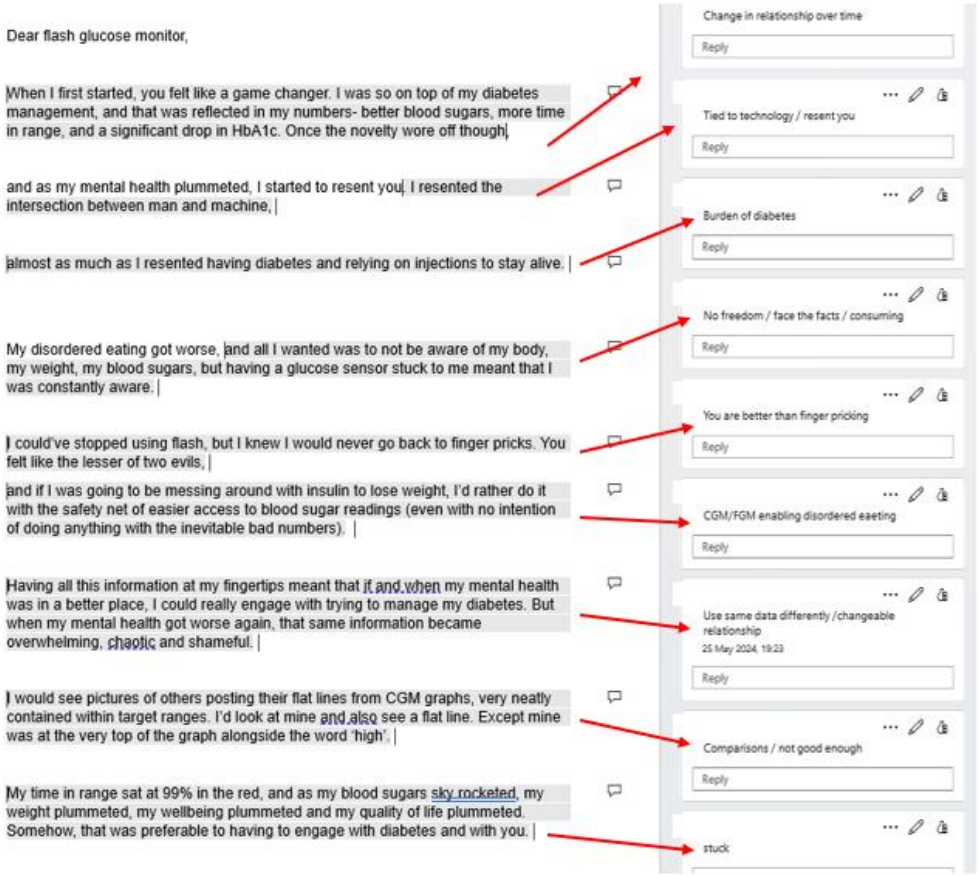
Appendix Q

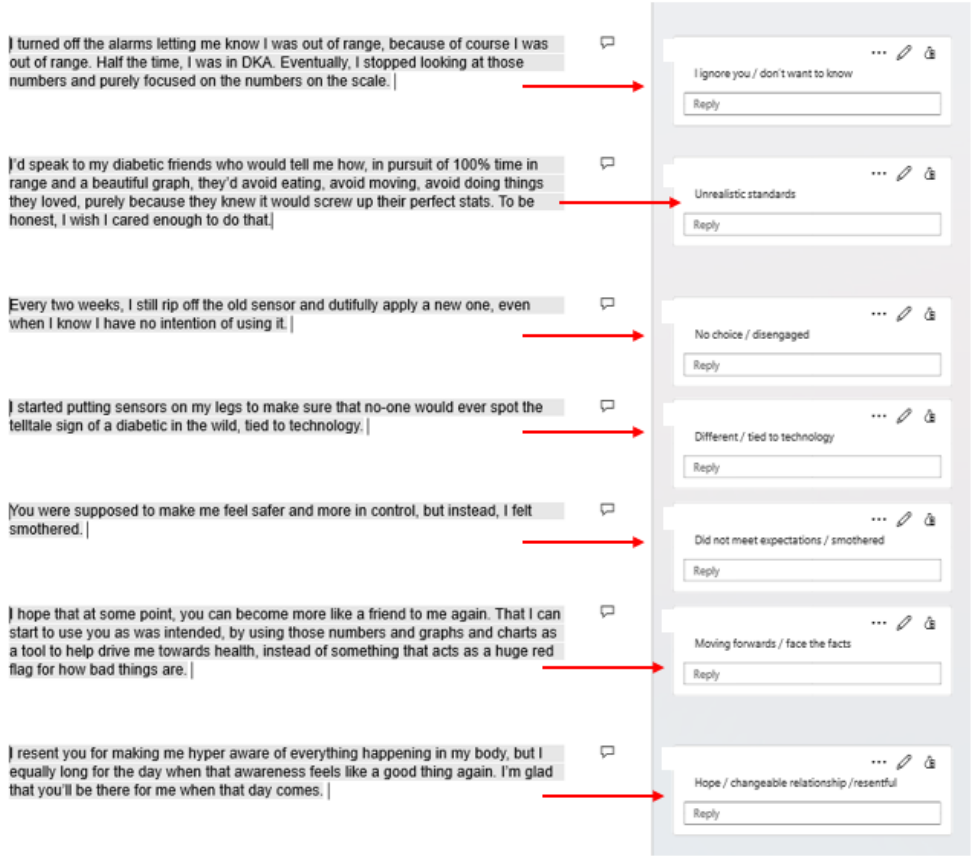
Extracts from coding process

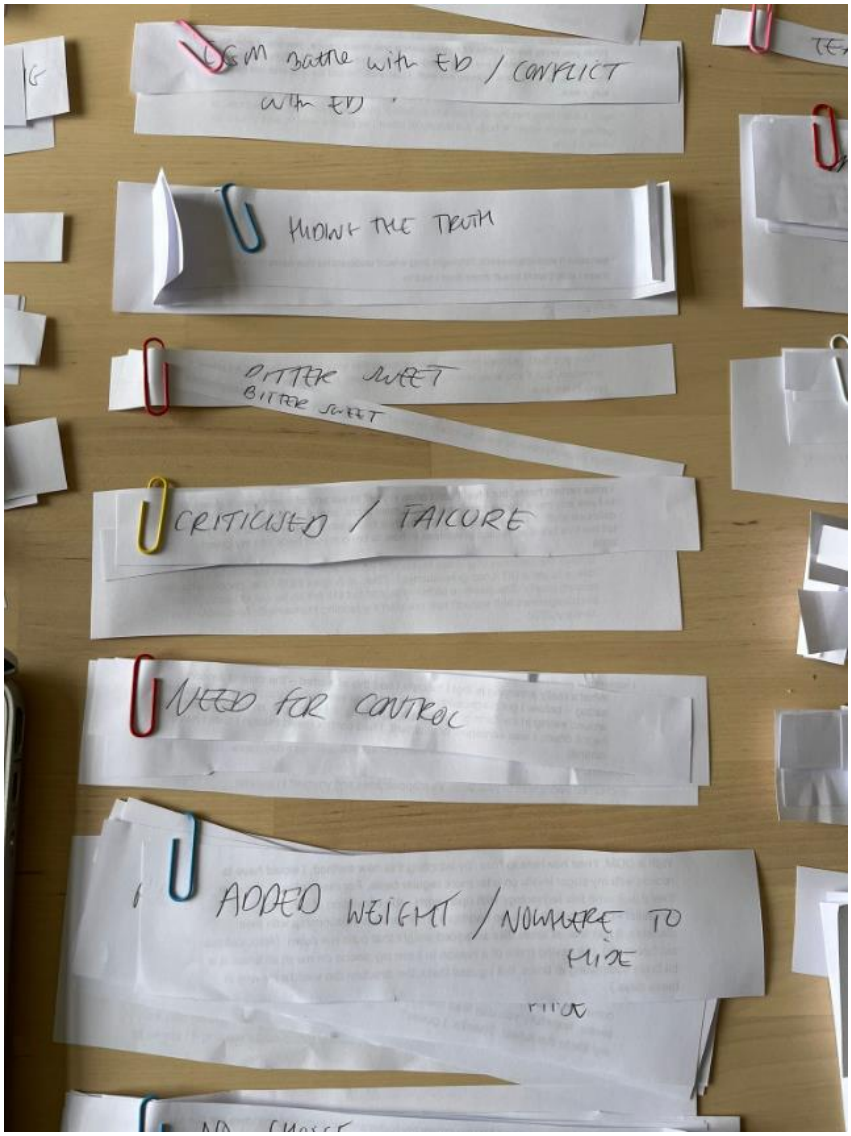
Familiarisation of data



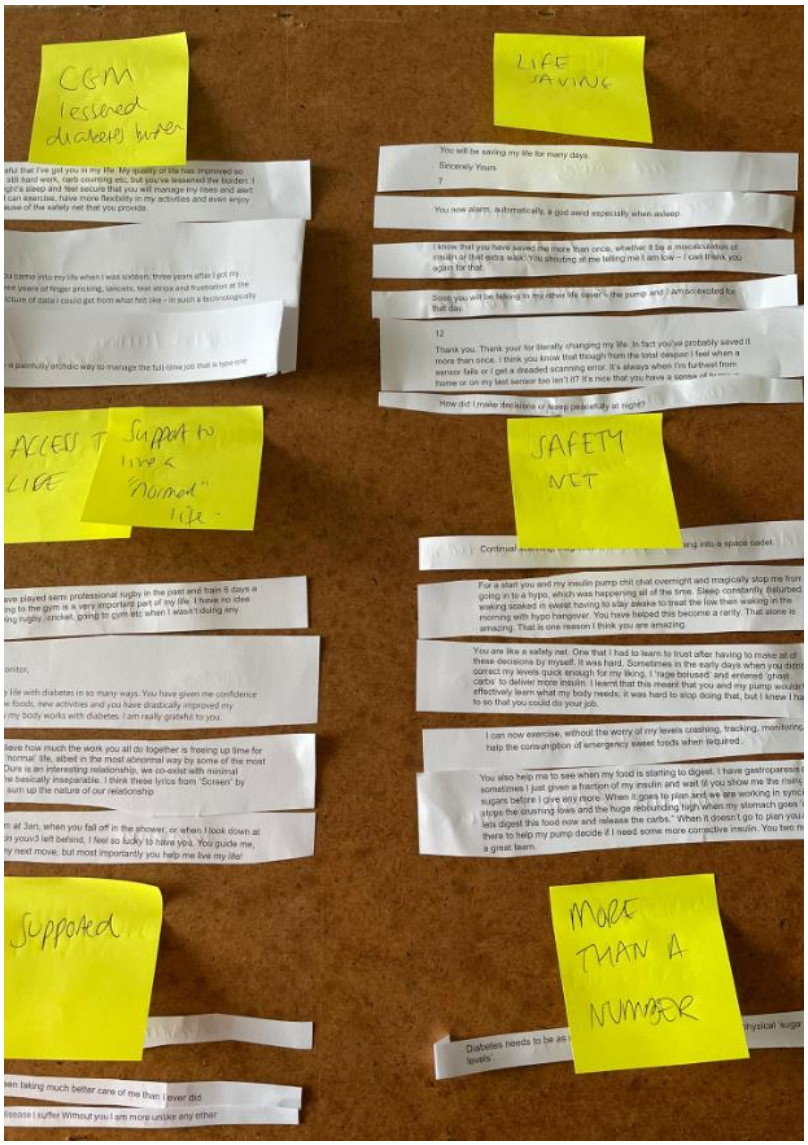
Generating codes and example coded letter



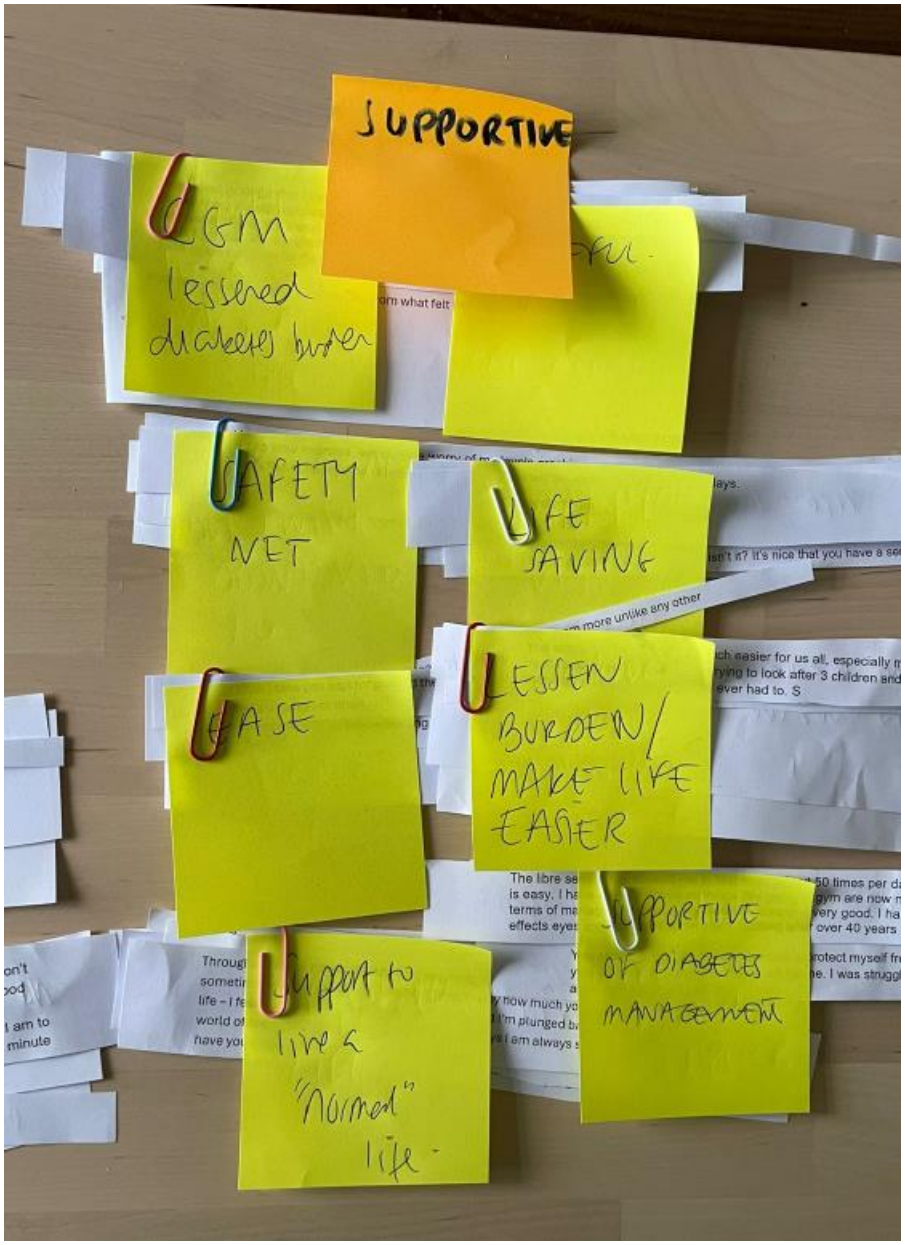

I turned off the alarms letting me know I was out of range, because of course I was out of range. Half the time, I was in DKA. Eventually, I stopped looking at those numbers and purely focused on the numbers on the scale.
I ignore you / don't want to know
Reply
I'd speak to my diabetic friends who would tell me how, in pursuit of 100% time in range and a beautiful graph, they'd avoid eating, avoid moving, avoid doing things they loved, purely because they knew it would screw up their perfect stats. To be honest, I wish I cared enough to do that.
Unrealistic standards
Reply
Every two weeks, I still rip off the old sensor and dutifully apply a new one, even when I know I have no intention of using it.
No choice / disengaged
Reply
I started putting sensors on my legs to make sure that no-one would ever spot the telltale sign of a diabetic in the wild, tied to technology.
Different / tied to technology
Reply
You were supposed to make me feel safer and more in control, but instead, I felt smothered.
Did not meet expectations / smothered
Reply
I hope that at some point, you can become more like a friend to me again. That I can start to use you as was intended, by using those numbers and graphs and charts as a tool to help drive me towards health, instead of something that acts as a huge red flag for how bad things are.
Moving forwards / face the facts
Reply
I resent you for making me hyper aware of everything happening in my body, but I equally long for the day when that awareness feels like a good thing again. I'm glad that you'll be there for me when that day comes.
Hope / changeable relationship /resentful
Reply

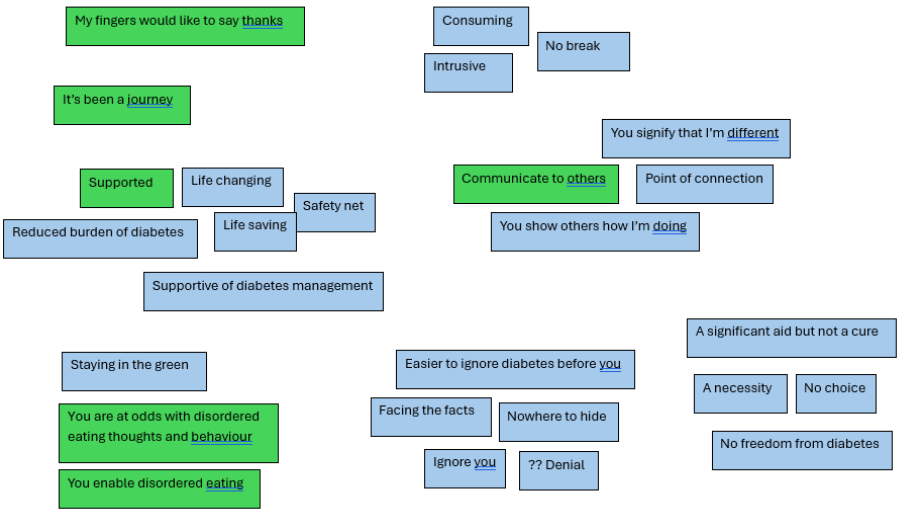

CGM battle with ED / CONFLICT
with ED
HIDING THE TRUTH
BITTER SWEET
BITTER SWEET
CRITICISED / FAILURE
NEED FOR CONTROL
ADDED WEIGHT / NOWHERE TO
HIDE

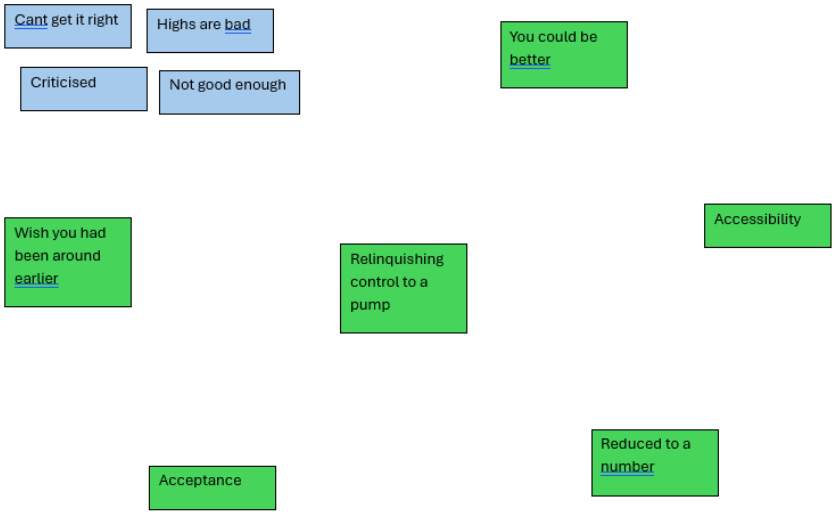
Generating initial themes

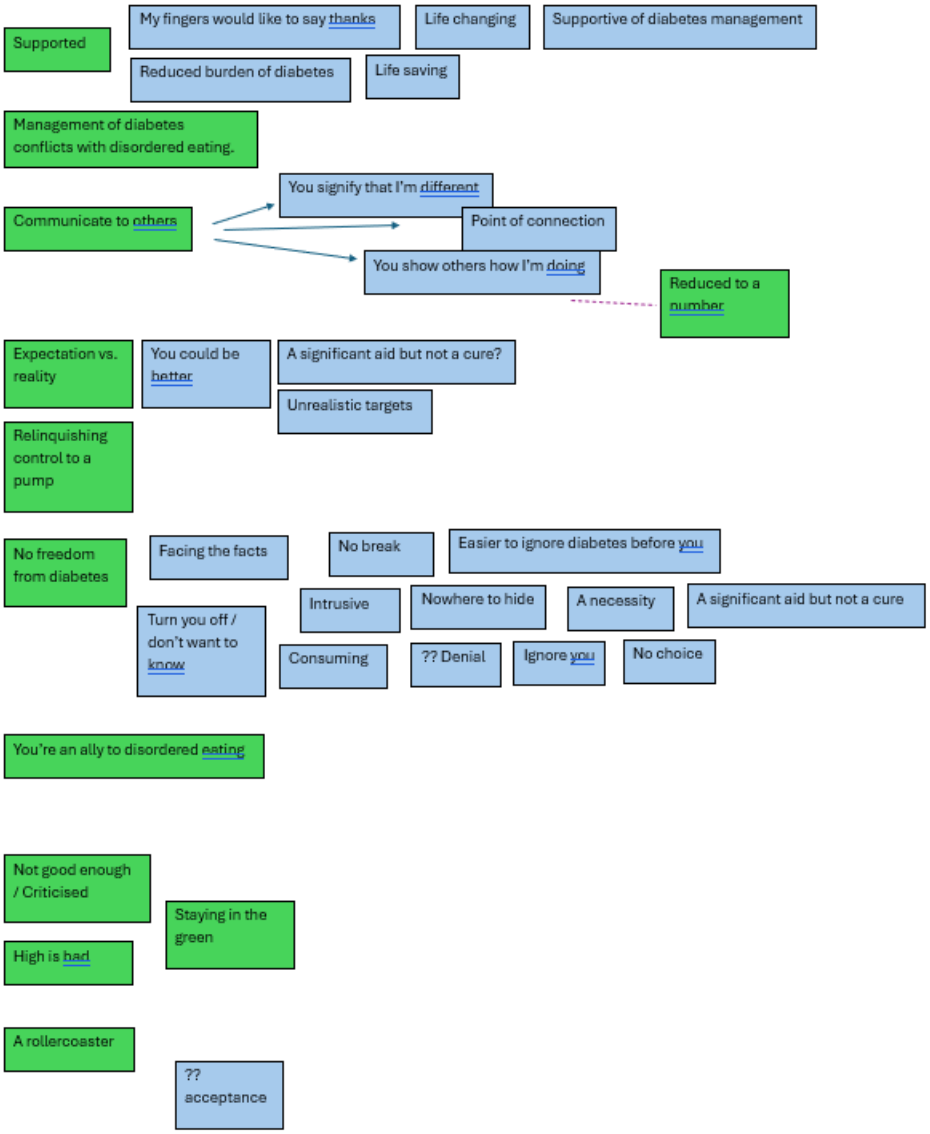


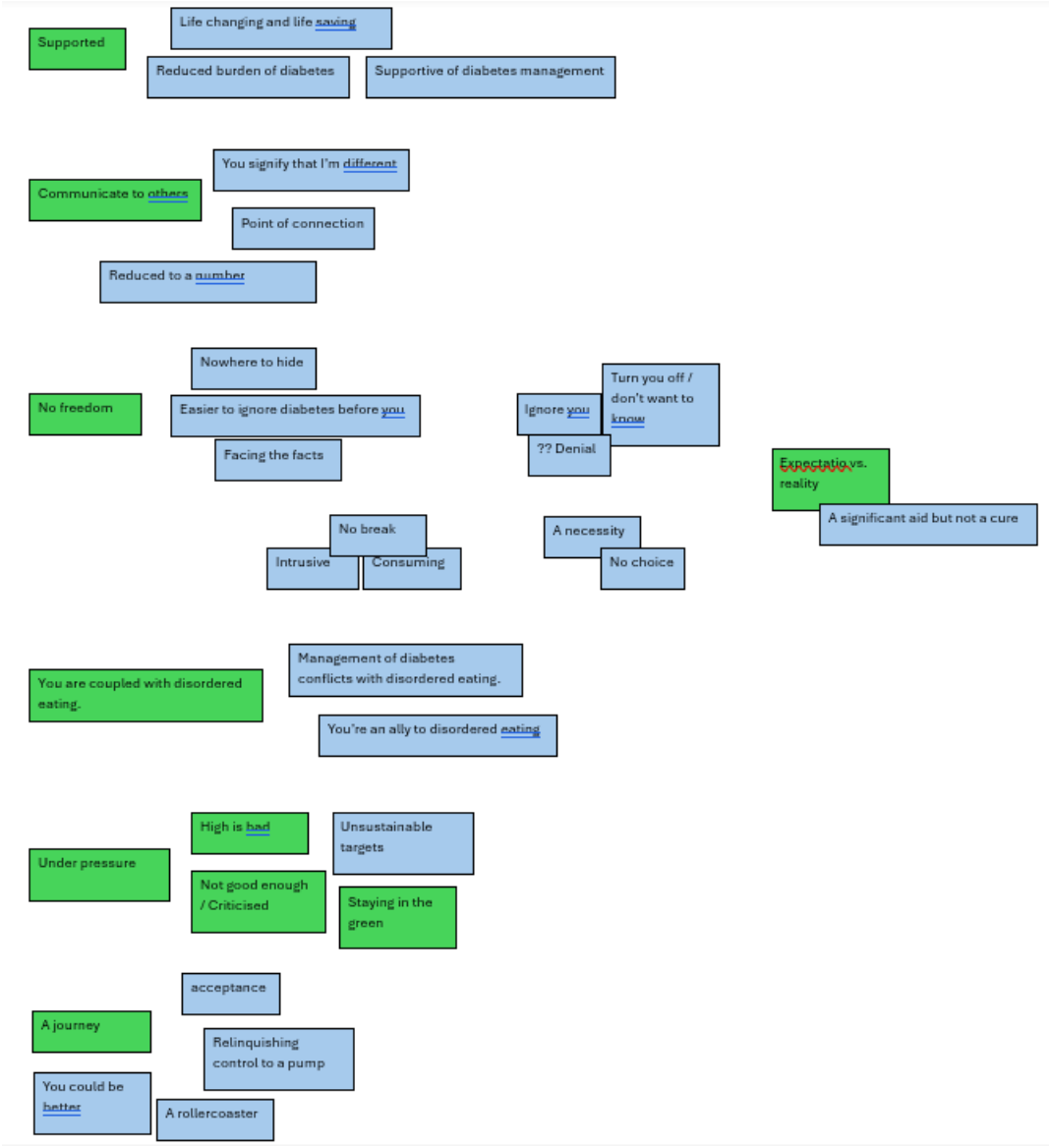

I LINK YOU WITH CALORIES
YOU ARE LIKE THE SCALES
CAN RELATE WITH ED
YOU WERE AROUND EARLIER
NO BREAK FROM YOU
INTRUSIVE
EATING TO STAY IN GREEN
FREEDOM FROM DIABETES
GRATEFUL
SAFETY NET
LESSEN BURDEN/ MAKE LIFE EASIER
SHAME / ASHAMED
WOULD RATHER NOT HAVE YOU
NECESSITY
NO CHOICE


SUPPORTIVE
CGM
lessened
diabetes burden
SAFETY
NET
LIFE
SAVING
EASE
LESSEN
BURDEN/
MAKE LIFE
EASIER
SUPPORTIVE
OF DIABETES
MANAGEMENT
support to
live a
"normal"
life

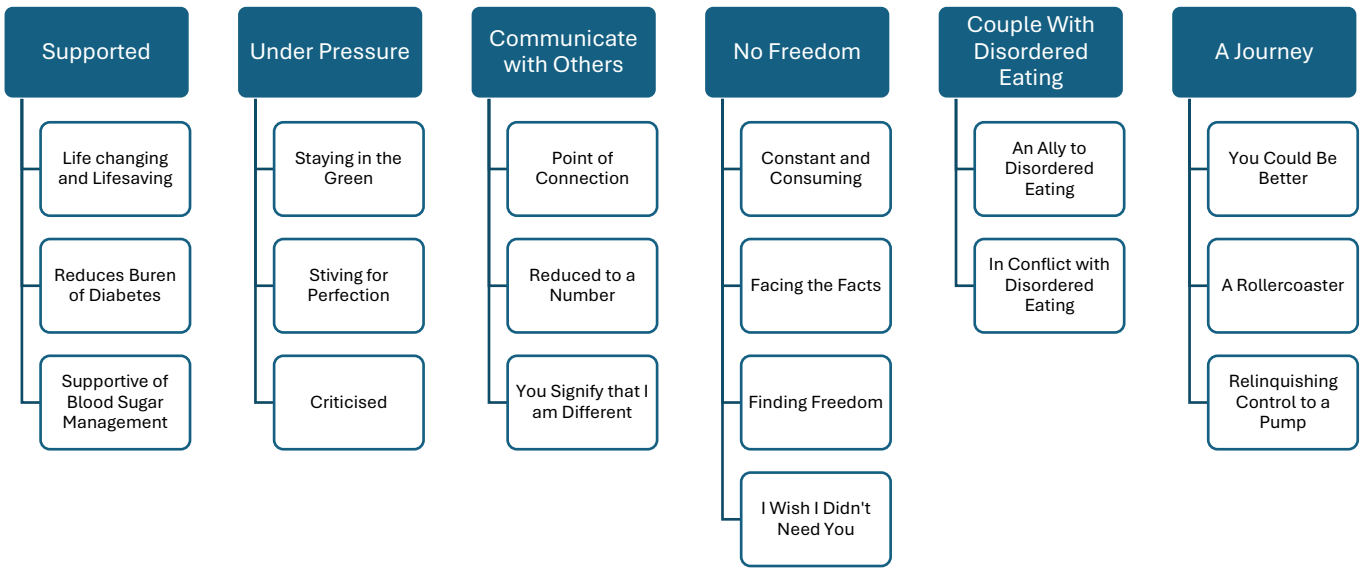

My fingers would like to say thanks
It's been a journey
Supported
Life changing
Safety net
Reduced burden of diabetes
Life saving
Supportive of diabetes management
Consuming
No break
Intrusive
You signify that I'm different
Communicate to others
Point of connection
You show others how I'm doing
Staying in the green
You are at odds with disordered eating thoughts and behaviour
You enable disordered eating
Easier to ignore diabetes before you
Facing the facts
Nowhere to hide
Ignore you
?? Denial
A significant aid but not a cure
A necessity
No choice
No freedom from diabetes

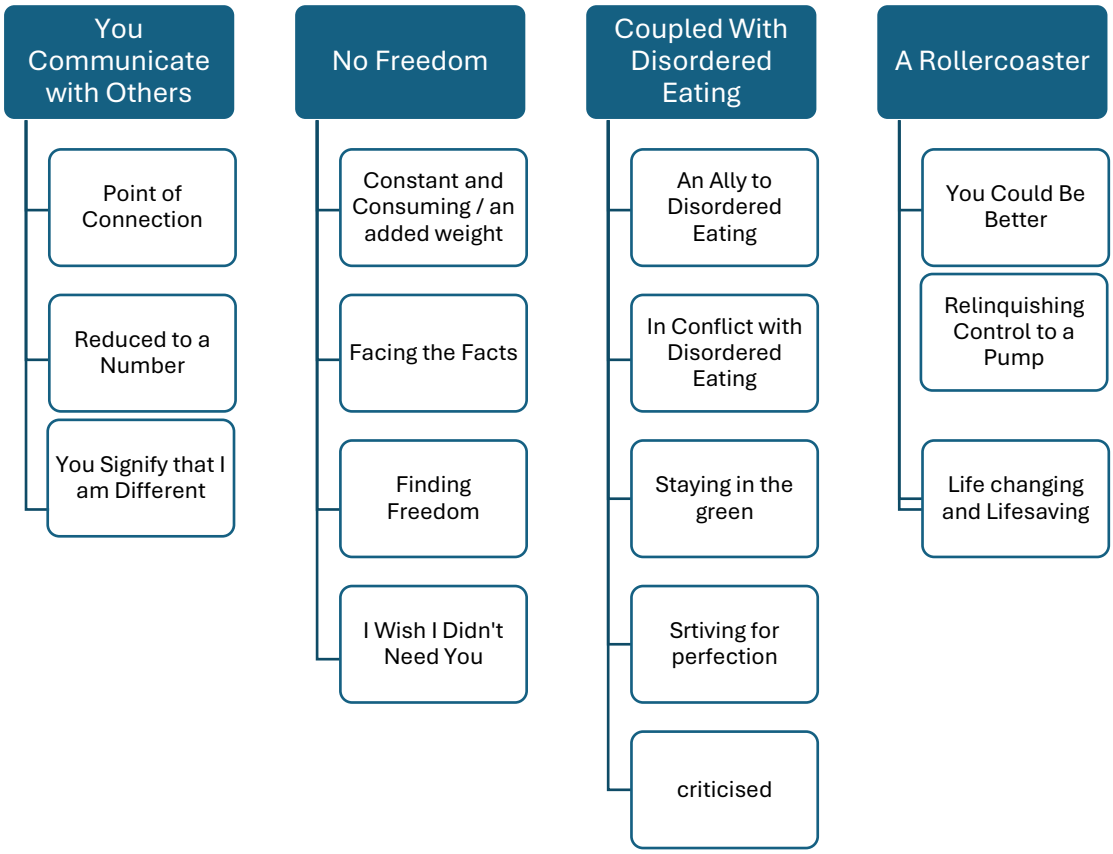

Cant get it right
Highs are bad
Criticised
Not good enough
You could be better
Wish you had been around earlier
Relinquishing control to a pump
Accessibility
Acceptance
Reduced to a number


Supported
My fingers would like to say thanks
Life changing
Supportive of diabetes management
Reduced burden of diabetes
Life saving
Management of diabetes conflicts with disordered eating.
Communicate to others
You signify that I'm different
Point of connection
You show others how I'm doing
Reduced to a number
Expectation vs. reality
You could be better
A significant aid but not a cure?
Unrealistic targets
Relinquishing control to a pump
No freedom from diabetes
Facing the facts
No break
Easier to ignore diabetes before you
Intrusive
Nowhere to hide
A necessity
A significant aid but not a cure
Turn you off / don't want to know
Consuming
?? Denial
Ignore you
No choice
You're an ally to disordered eating
Not good enough / Criticised
Staying in the green
High is bad
A rollercoaster
?? acceptance


Supported
Life changing and life saving
Reduced burden of diabetes
Supportive of diabetes management
Communicate to others
You signify that I'm different
Point of connection
Reduced to a number
No freedom
Nowhere to hide
Easier to ignore diabetes before you
Facing the facts
Ignore you
Turn you off / don't want to know
?? Denial
Expectatio vs. reality
A significant aid but not a cure
No break
Intrusive
Consuming
A necessity
No choice
You are coupled with disordered eating.
Management of diabetes conflicts with disordered eating.
You're an ally to disordered eating
Under pressure
High is bad
Unsustainable targets
Not good enough / Criticised
Staying in the green
acceptance
A journey
Relinquishing control to a pump
You could be better
A rollercoaster

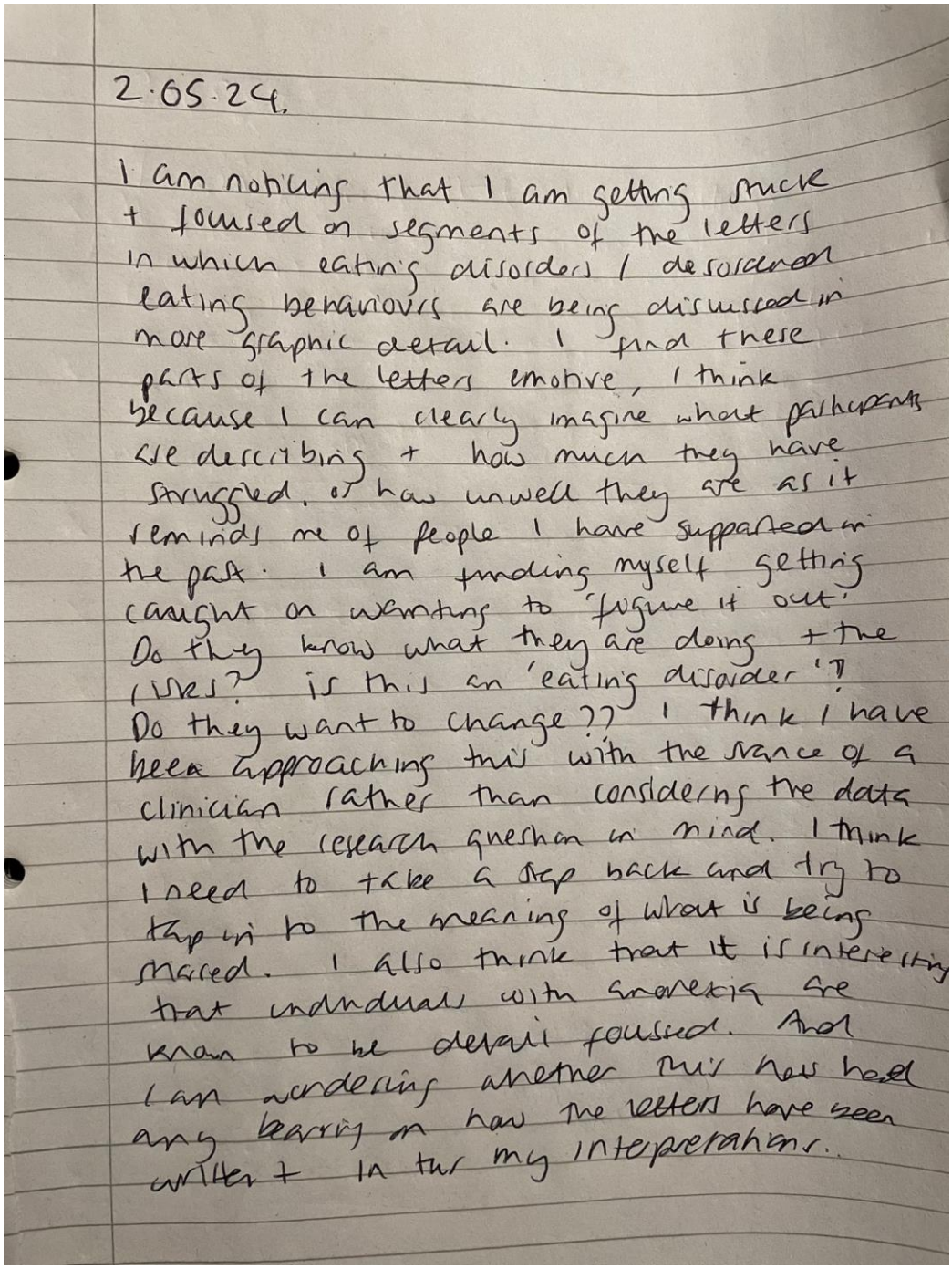
Reviewing potential themes


Supported
Life changing and Lifesaving
Reduces Buren of Diabetes
Supportive of Blood Sugar Management
Under Pressure
Staying in the Green
Stiving for Perfection
Criticised
Communicate with Others
Point of Connection
Reduced to a Number
You Signify that I am Different
No Freedom
Constant and Consuming
Facing the Facts
Finding Freedom
I Wish I Didn't Need You
Couple With Disordered Eating
An Ally to Disordered Eating
In Conflict with Disordered Eating
A Journey
You Could Be Better
A Rollercoaster
Relinquishing Control to a Pump


You Communicate with Others
Point of Connection
Reduced to a Number
You Signify that I am Different
No Freedom
Constant and Consuming / an added weight
Facing the Facts
Finding Freedom
I Wish I Didn't Need You
Coupled With Disordered Eating
An Ally to Disordered Eating
In Conflict with Disordered Eating
Staying in the green
Srtiving for perfection
criticised
A Rollercoaster
You Could Be Better
Relinquishing Control to a Pump
Life changing and Lifesaving

Appendix R

Journal Excerpt

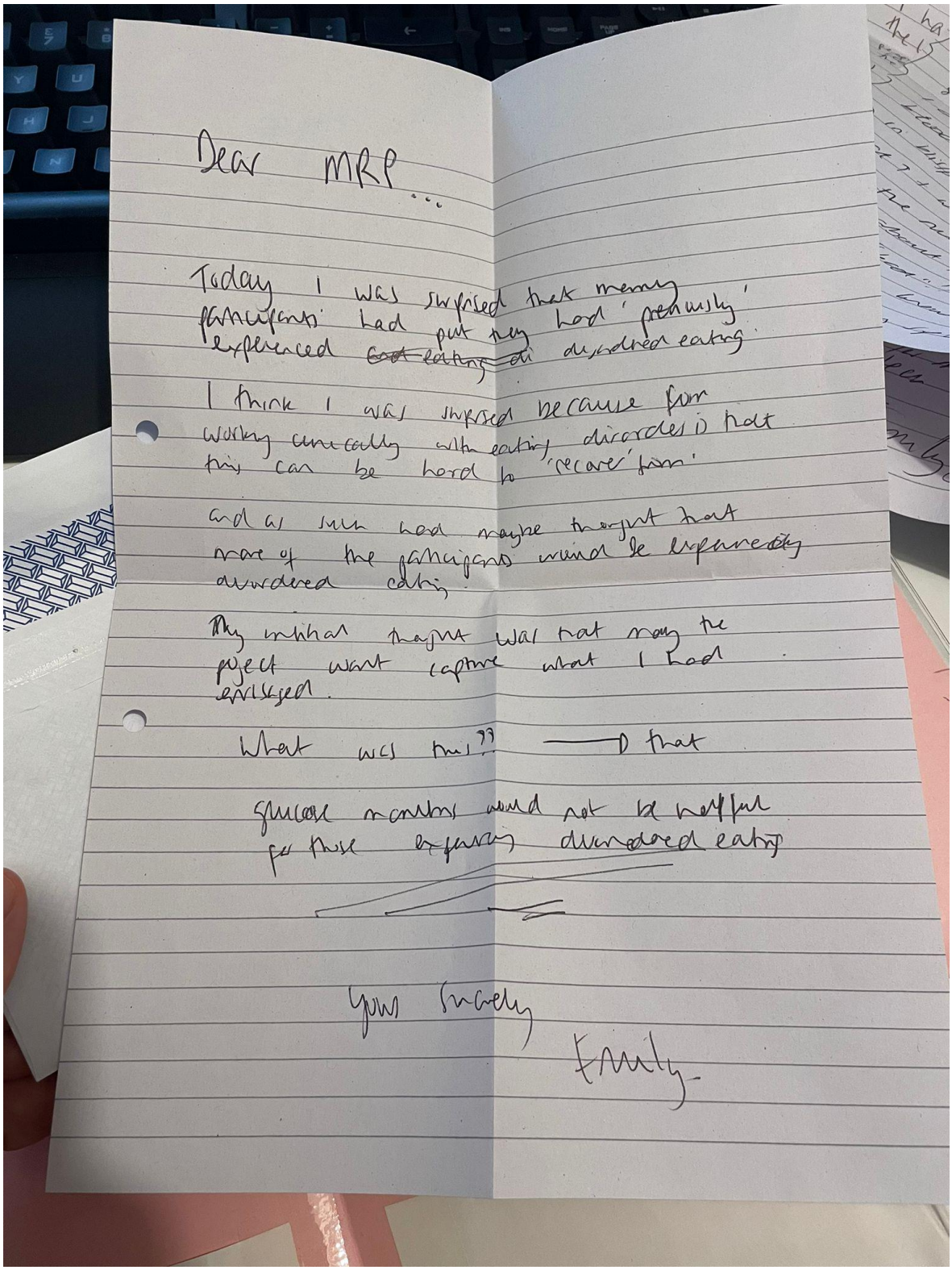


2.05.24.

I am noticing that I am getting stuck + focused on segments of the letters in which eating disorders / disordered eating behaviours are being discussed in more graphic detail. I find these parts of the letters emotive, I think because I can clearly imagine what participants are describing + how much they have struggled, or how unwell they are as it reminds me of people I have supported in the past. I am finding myself getting caught on wanting to 'figure it out' Do they know what they are doing + the risks? is this an 'eating disorder'? Do they want to change?? I think I have been approaching this with the stance of a clinician rather than considering the data with the research question in mind. I think I need to take a step back and try to tap in to the meaning of what is being shared. I also think that it is interesting that individuals with anorexia are known to be detail focused. And I am wondering whether this has had any bearing on how the letters have been written + in turn my interpretations.

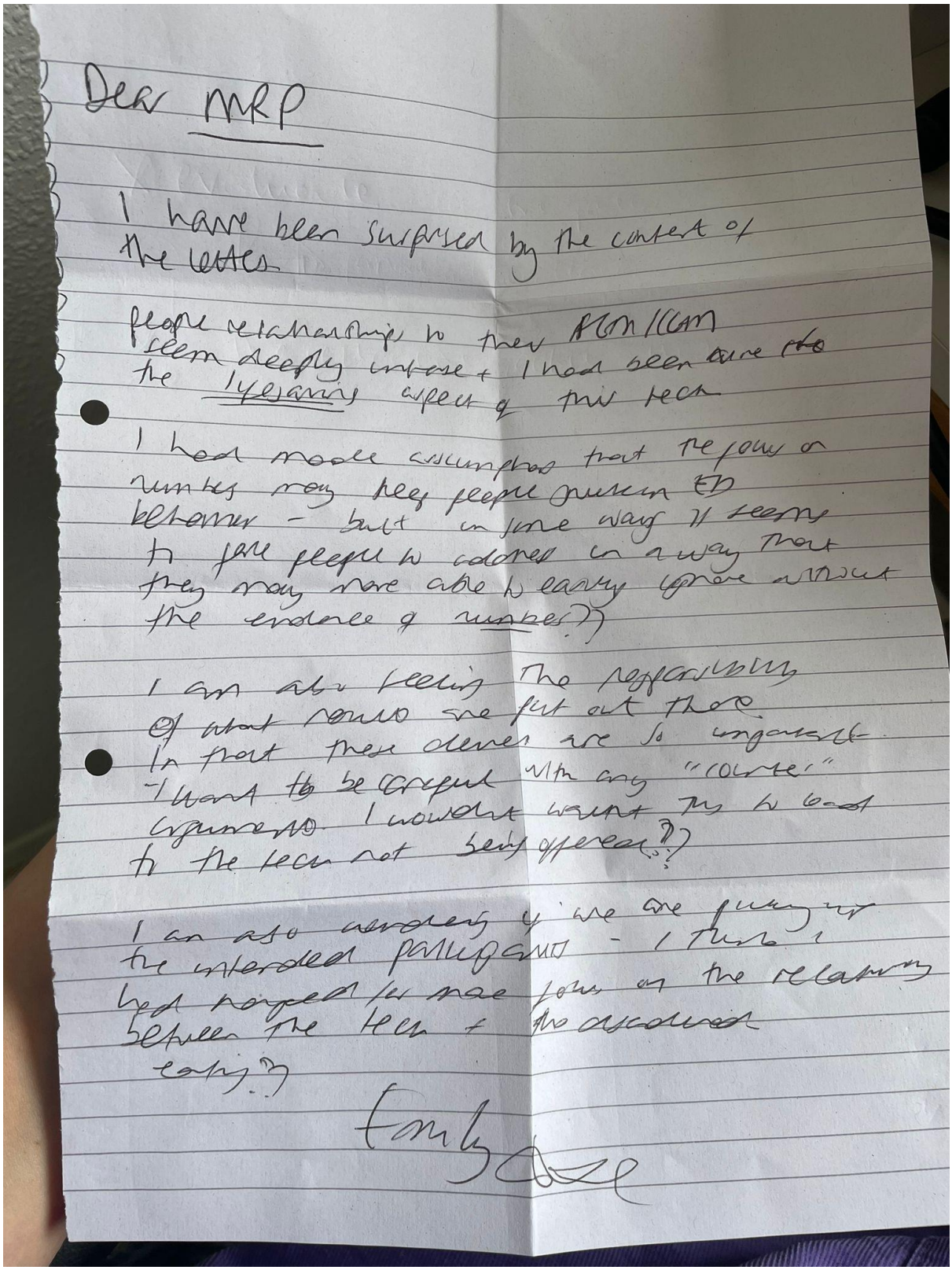
Appendix S

Example of reflective letter written to thesis during recruitment



Appendix T

Example of reflective letter written to thesis during data collection



Appendix U

Example of letter written to CGM