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## PROFESSIONAL DOCTORATES

### Turning the T1DE: Recovery Factors in Type 1 Disordered Eating

Embick, Ronda

*Award date:*  
2023

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**Turning the TIDE: Recovery Factors in Type 1 Disordered Eating**



PRIFYSGOL  
**BANGOR**  
UNIVERSITY

**Ronda Embick**

**North Wales Clinical Psychology Programme**

**Submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology  
(DClinPsy)**

**October 2023**

## **Table of Contents**

<b>Thesis Declaration</b> .....	2
<b>Acknowledgements</b> .....	3
<b>Thesis Abstract</b> .....	5
<b>Chapter 1: Systematic Review</b> .....	6
<b>Abstract</b> .....	8
<b>Introduction</b> .....	9
<b>Methods</b> .....	12
<b>Results</b> .....	14
<b>Conclusions</b> .....	38
<b>References</b> .....	41
<b>Appendix B: MMAT Checklist</b> .....	50
<b>Chapter 2: Empirical Paper</b> .....	52
<b>Introduction</b> .....	54
<b>Method</b> .....	59
<b>Results</b> .....	63
<b>Discussion</b> .....	77
<b>References</b> .....	82
<b>Appendix A: Confirmation of Ethical Approval by Bangor University School of Psychology</b> 85	
<b>Appendix B: Research Protocol Submitted to Ethics</b> .....	86
<b>Appendix C: Participant Forms</b> .....	98
<b>Appendix D: Interview Guide</b> .....	106
<b>Appendix E: Examples of Analytic Process: Memos and Transcript Sections</b> .....	107
<b>Appendix F: Table of Codes and Additional Quotations</b> .....	110
<b>Chapter 3: Contributions to Theory and Clinical Practice</b> .....	118
<b>References</b> .....	133
<b>Word Count</b> .....	135

## Thesis Declaration

Declaration to include in your thesis I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.

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Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw'r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o'r blaen ar gyfer unrhyw radd, ac nid yw'n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deul cymeradwy.

Signed: Ronda Embick

Date: 2.10.23

## **Acknowledgements**

I would first like to acknowledge and thank everyone who participated in this study and made this research possible. I feel so privileged to have been able to hear your stories and I hope I have been able to give your narratives justice. I was honestly struck by how passionate the thirteen individuals who participated in this study were in wanting to support others going through similar experiences. I hope it helps to know that the information you gave me was rich in information and so helpful.

Next, I would like to thank my research supervisors. First to Mike, my academic research supervisor, for your guidance on the research process and helpful words when I needed to take a step away due to personal circumstances. To Rose, for your expert advice and passion. Thank you for helping me push through this process and reminding me to look after myself. You might not remember this, but I remember what you told me in second year when I was struggling with a very different assignment “Don’t let this break you.” You then proceeded to tell me to pick myself back up and added in a perfect balance of compassion to this. When things got tricky, I kept reminding myself of this. And lastly, of course, thank you for rewarding me with pictures of cats each time I finished a step of the process.

Thank you to Elizabeth, my training coordinator. You have been so helpful throughout this process. Thank you for having a listening ear, for being encouraging, and for helping me through some difficult decisions when I needed to take some time out and step away from things.

Lastly, to my friends and family that in some way have shaped me and helped me in this journey. This last three years have been tougher than I could have ever imagined. Training is difficult on its own, but the life changes that have occurred this last year have made it even more of a challenging time. I never would have gotten through this if it wasn’t for the many people that helped me along the way.

To Miriam, thank you for being there and reminding me that I can do it. I think if it wasn't for you, I'm not sure I would have applied for that assistant psychologist post that got me started on this journey. Thank you for seeing my strengths and reminding me of these when things were difficult. To Jason, thank you for the sacrifices you made along the way. Especially for trekking across the country for me so that I could take on the opportunities I was given. To all of you on the discord server, thank you for the random chats and gaming distractions. It's been so weird and wonderful reconnecting with you all again. To my mother, thank you. You were given some difficult cards in life, and I know things have not been easy. I hope you can heal, and I hope you are proud of me.

Thank you to the cohort. It's been such an interesting journey, from trying to do roleplays wearing visors and practicing social distancing to saying our goodbyes on literally the hottest day of the year. A special thank you to Hannah and Steph for being there to support me through these extra hurdles I faced at the end. I truly appreciated you both checking in, listening, and reminding me that I was nearly there. Not to mention thank you for the laughs when things have felt dark, the Harry Styles and Taylor Swift masks will forever make me laugh when I think of them!

To Joel, thank you for reminding me of my potential and seeing the good in me when I have been at my worst. Thank you for brightening up my life and showing me a whole new world that I could have never imagined was possible. You have been able to make me laugh even when I've been close to tears and when the tears did inevitably strike, you were there armed with tissues and hugs. Lastly, thank you for reminding me to take breaks, drink water, and look after myself.

## Thesis Abstract

This thesis explores various factors that affect individuals living with type 1 diabetes. Chapter one of the thesis begins by presenting a systematic review of nineteen studies that examine the relationship between stigma and diabetes management. These studies include both quantitative and qualitative data, with all nineteen revealing that stigma negatively affects the management of type 1 diabetes. Limitations include that all nine quantitative studies were correlational, and there was a lack of standardisation across measures, making it difficult to compare results between studies. Qualitative studies found that stigma can affect the uptake of technology, self-care activities, disclosure, and system-wide barriers. This review highlights the need for interventions to target stigma at individual and systemic levels. The review also highlights the lack of research on intersecting stigmas.

Chapter two presents a grounded theory study exploring the concept of recovery within type 1 disordered eating (T1DE). Thirteen people met the study criteria and participated in semi-structured interviews. Five major categories were linked to the process of recovery and are presented as the 5Rs of recovery. These include readiness to change, roadblocks, recovery factors, risk factors, and relapse. Underpinning each category is a combination of biological, psychological, social, and systemic factors. Recommendations include that this tool is shared amongst teams and individuals to improve understanding of recovery in this area and that services consider how they can facilitate the listed recovery factors and limit barriers.

The final chapter further explores the clinical and research implications of the findings presented earlier. It emphasises the importance of psychological support in diabetes services and addresses the systemic issues highlighted in the previous two chapters. The chapter concludes with a reflective commentary on the research process.



## **Chapter 1: Systematic Review**

# The Impact of Stigma on the Management of Type 1 Diabetes: A Systematic Review

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This paper has been prepared following the submission guidelines for *Diabetic Medicine*:  
<https://onlinelibrary.wiley.com/page/journal/14645491/homepage/forauthors.html>

## **Abstract**

**Aims:** To systematically review the literature to understand how stigma affects the management of type 1 diabetes.

**Methods:** Systematic review protocol was followed in accordance with PRISMA guidelines. Both quantitative and qualitative data were considered. Included papers were subject to quality assessment.

**Results:** Nineteen articles met the inclusion criteria and were included in the final analysis. Amongst these, one study was mixed methods, nine were qualitative, and nine were quantitative. All nineteen studies found a negative relationship between stigma and type 1 diabetes management. Limitations include that all nine quantitative studies were correlational, and there was a lack of standardisation across measures. Qualitative studies provided a further understanding of the effects observed in the quantitative studies. They found that stigma can affect the uptake of technology, self-care activities, disclosure, and system-wide barriers. Intersectional stigma was also observed.

**Conclusions:** This review highlights the need for interventions to target stigma on both an individual and a systematic level. Professionals should consider how intersecting stigmas may also add to the burden of living with type 1 diabetes.

**KEYWORDS:** Diabetes mellitus, type 1; stigma; shame; psychological distress; systematic review; psychology.

## Introduction

The term 'stigma' originates from the Greeks who used the word to refer to marks placed on the body to expose someone for being 'unusual and bad'<sup>1</sup>. These marks were used to convey to others that the bearer of the mark could be a criminal or traitor and that they should be avoided. Goffman's theory on stigma is a psychological theory that proposes that we use a similar meaning of the word stigma today, except that it is applied to wider characteristics and attributes of a person that deviate from the 'social normal' than that of a specific mark inflicted on someone. Goffman<sup>1</sup> proposes that we have numerous identities that influence how we experience the world. As one of our primary goals in a social interaction is to avoid embarrassment, we may conceal some of the identities that might not be viewed favourably. When we meet someone new, we initially characterise or group them to understand if they share similar stigmas to ourselves. If we do not feel someone shares these then we may avoid stigmatisation by not disclosing parts of our identity that are not shared.

Health-related stigmatisation is a social process where negative characteristics are attributed to an individual with a health condition<sup>2</sup>. Stigmatisation can take two forms: Enacted stigma and felt stigma<sup>3</sup>. Enacted stigma refers to when others act on perceived negative characteristics, either directly or indirectly, leading to exclusion, rejection, blame, discrimination, or devaluation<sup>2,3</sup>. Whereas felt stigma, or internalised stigma, is when an individual believes that negative characteristics have been attributed to them and fears that others will act on these<sup>3,4</sup>. Felt stigma has been linked to feelings of shame, guilt, and behaviours such as withdrawal or concealment<sup>3,4</sup>. Research into health-related stigma has shown that stigma impacts the management of various health conditions, including HIV, leprosy, tuberculosis, cancer, and epilepsy<sup>2,4,5</sup>. Both forms of stigma, enacted and felt, have been shown to present barriers to health-seeking behaviour, engagement in care, and treatment adherence<sup>2,4,5</sup>. Although this phenomenon has been associated with many physical

health conditions, few reviews have been undertaken to understand the extent of current research on type 1 diabetes.

A study conducted in The United States found that 76% of respondents with type 1 and 52% of respondents with type 2 felt that diabetes comes with stigma<sup>6</sup>. Due to the nature of the condition, people living with diabetes must undertake numerous self-care activities, such as continuous monitoring of blood glucose levels and administering insulin to avoid complications<sup>7</sup>. Undertaking these essential tasks in public may make an individual more susceptible to unwanted attention and more likely to experience diabetes-related stigma<sup>8</sup>. Whilst the development of diabetes technology may have eased the burden of some of these tasks, the visibility of diabetes technology such as insulin pumps or continuous glucose monitors (CGMs) also runs the risk of increasing the visibility of the condition and furthering unwanted negative attention<sup>9</sup>.

Stigma impacts not only individuals living with chronic health conditions but also the wider system surrounding the individual, including healthcare professionals, communities, policies, parents, and caregivers<sup>10</sup>. An increased understanding of the knowledge surrounding stigma may improve the quality of care and support an individual may receive. For instance, a health professional who understands the difficulties a young adult may face with stigma may offer more compassionate care, which may counteract some of the adverse effects of stigma and other burdens individuals with diabetes may face. Therefore, it is essential to understand the current research in this area.

A review on the relationship between type 2 diabetes and stigma revealed that stigma was associated with adverse health outcomes, including impacts on glycaemia and engagement in self-management behaviours<sup>11</sup>. To the knowledge of the authors, only one review has been published regarding the effects of stigma on type 1 diabetes<sup>12</sup>. This review focused on the experience of individuals living with type 1 diabetes as well as their

caregivers and found that stigma can have a negative impact on sociocultural factors such as discrimination at work, finding a partner and overall quality of life. Our current review differs in that it follows PRISMA guidelines and specifically focuses on the direct impact of stigma on diabetes management.

The objective of this systematic review was, therefore, to systematically review the existing literature on the impact that stigma has on self-management and diabetes outcomes for individuals living with type 1 diabetes. It was anticipated that various methodologies would be used to capture this information, so both quantitative and qualitative data were considered.

## Methods

The systematic review protocol was followed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines<sup>13</sup>. The review was pre-registered with the International Prospective Register of Systematic Reviews (PROSPERO), reference number CRD42022376869.

### *Search Strategy*

A literature search was conducted across two search engines (Pro-Quest and Ebscohost) to access four databases (ASSIA, PsychINFO, Medline, and CINAHL). Articles between January 2013 and April 2023 were sought. The rationale for looking at the last 10-year period was due to changing concepts such as stigma or diabetes regarding access to technology and management guidelines. The searches were re-run on the 11<sup>th</sup> of September 2023 to retrieve any further studies for inclusion, but this did not yield any additional articles.

The search script was as follows:

```
(title(("Type 1" OR "Insulin Dependent Diabetes Mellitus")) OR abstract(("Type 1" OR "Insulin Dependent Diabetes Mellitus"))) AND (title((Stigma* OR Shame* OR discriminat* OR prejudice* OR self-stigma* OR blame* OR self-blame*OR guilt* OR fault* OR self-disgust*)) OR abstract((Stigma* OR Shame* OR discriminat* OR prejudice* OR self-stigma* OR blame* OR self-blame*OR guilt* OR fault* OR self-disgust*))).
```

### *Eligibility Criteria*

The first author screened all titles and abstracts. At this stage, reliability checks were carried out independently using checks by the second author. The second author randomly reviewed twenty-five of the screened articles. Both authors agreed on the articles chosen and excluded, so no queries were raised during this process. To be eligible for inclusion in this review, papers were required to report on the association between stigma and either diabetes

outcomes (i.e., Hb1Ac), treatment adherence, or self-management tasks. The article's primary focus had to be on the individual living with type 1 diabetes, and any articles looking at type 1 and type 2 needed to differentiate between the two in the results section clearly. Articles excluded were studies without a methodology and studies that focused solely on the account of stigma from the perspectives of parents, carers, or healthcare professionals.

#### *Data Extraction and Quality Assessment*

Extracted data were entered into a spreadsheet with the following information: Publication data, country, age of participants, sample size, type of study, outcome measures, and results/findings. Data extracted were initially entered by the first author and cross-checked and compared by the other authors.

Due to the variability across studies, a tool that could appraise all methodologies was sought. The Mixed Methods Appraisal Tool (MMAT) was used to evaluate articles as it showed reliability and validity when assessing studies utilising qualitative, quantitative, and mixed methodologies<sup>14</sup>. The MMAT was initially completed by the first author and reviewed by the other two authors.

#### *Data Synthesis and Analysis*

A narrative synthesis was conducted to summarise the key findings. Conducting a meta-analysis was not feasible due to the heterogeneity between the study designs and the outcome measures used, so quantitative findings are summarised descriptively. Characteristics of the included studies were exported into a spreadsheet where they were compared. This was converted to a table, which is present in the review (see Table 1), and a narrative synthesis of the data took place.

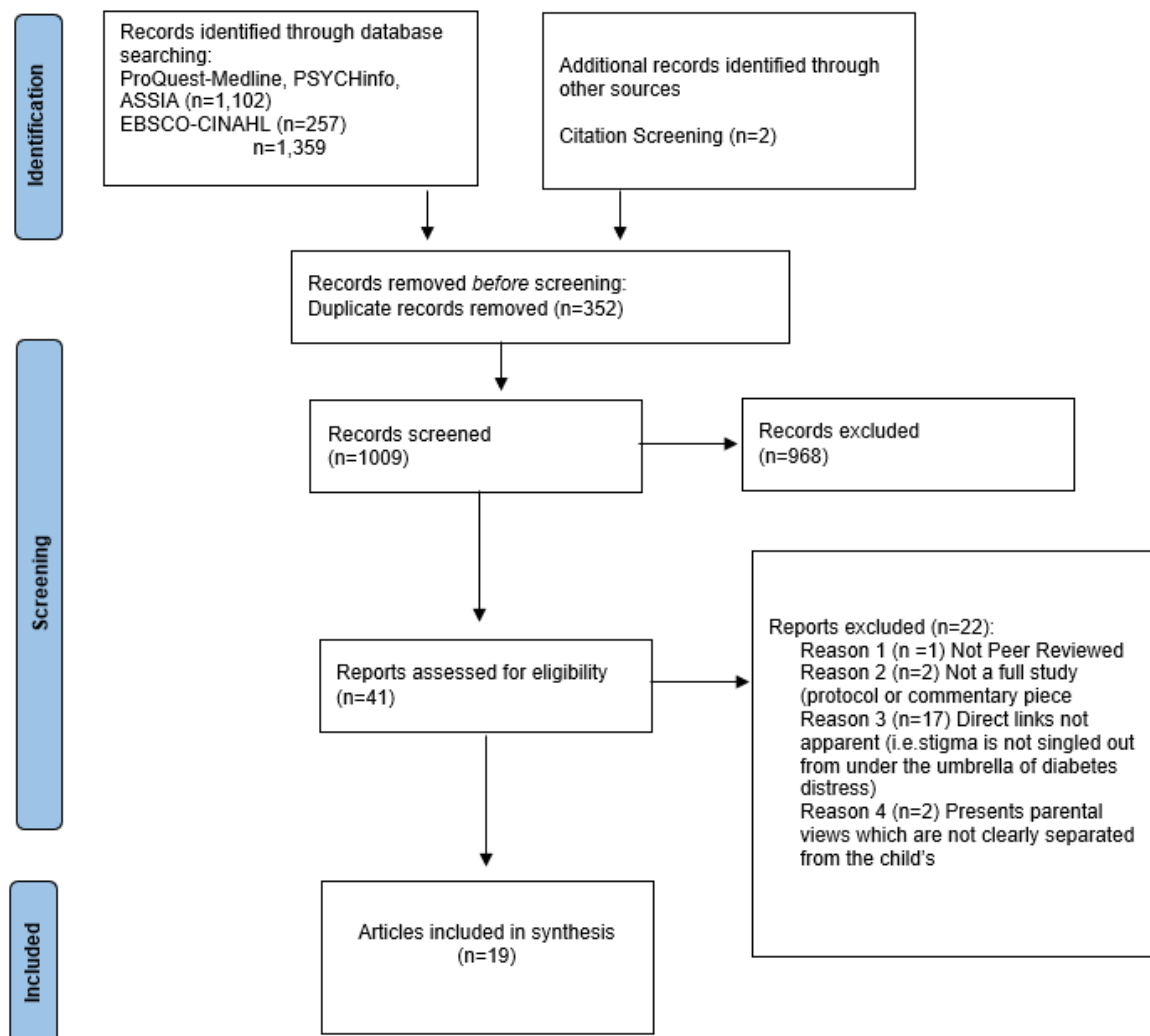


## Results

The initial search generated 1359 articles. Two articles were found through citation searching, and 352 duplicates were removed. Titles and abstracts of the remaining 1,009 articles were screened using the eligibility criteria. After the full-text screening, nineteen articles were chosen for the final analysis (including the two from citation screening).

**Figure 1**

*PRISMA* Flow Diagram



### *Screening and Selection*

After full-text screening, nineteen studies were included in the final analysis. Figure 1 depicts the rationale for reports being excluded. Few studies examined the impact of stigma and shame on diabetes management in isolation from other factors. Studies that examined multiple psychosocial factors were included when stigma and shame were separated from other variables. In some articles, stigma was included amongst other factors and grouped into a concept known as ‘diabetes distress’. Unfortunately, these studies were not considered if variables were not separated, as it was impossible to determine the degree to which stigma impacted diabetes management when reported with other factors. Whilst these are essential factors to consider when supporting an individual with diabetes, they were beyond the scope of this paper.

Likewise, some studies used participants with type 1 diabetes and participants with type 2 diabetes or interviewed individuals living with diabetes alongside caregivers or medical professionals. Studies that separated results to align with the scope of this paper's inclusion criteria were still included, and only results for the targeted population were reported in Table 1.

### *Characteristics of included studies*

Table 1 shows studies arranged chronologically and then alphabetically by the first author's last name. Publication dates of the final nineteen studies ranged from 2013 to 2023 across eleven territories. Nine studies were qualitative, nine were quantitative, and one was a mixed-methods study. Qualitative papers used thematic analyses, content analyses, and grounded theory. All quantitative papers found were correlational.

Samples sizes for the identified studies ranged from 10 to 1,572. Age groups of participants varied. Two studies focused specifically on young adults<sup>15,16</sup>, six studies focused specifically on the experience of adolescents<sup>17-22</sup>, and one study focused on the experience of children<sup>23</sup>. The remainder of studies ( $n=10$ ) covered across the lifespan or did not specify a target age group. Most studies ( $n=14$ ) reported the duration participants had been diagnosed with type 1 diabetes. Nine studies did not include information about the number of participants on an insulin pump. In one study, having an insulin pump was an exclusion criterion<sup>18</sup>.

**Table 1**

Summary of studies included in this review.

Study and Location	Population of Interest	Aims	Design and Applicable Measures	Outcomes	Limitations
<b>Quantitative Studies</b>					
Liu et al. (2017) United States <sup>6</sup>	1,572 Participants with type 1 diabetes  Age groups of people with Type 1: 13% Children 77% Adults 10% Seniors  38% Male 64% Female  92% on a pump  Average diabetes duration not specified	Measure diabetes stigma and its psychosocial impact.	Correlational.  Online survey with self-reporting measures for health and demographic details, diabetes treatment behaviours, and attitudes concerning diabetes management.  'Poor diabetes management' is defined by a HbA1c* >7%.	A significantly greater percentage of respondents with type 1 diabetes reported diabetes stigma than those with type 2 diabetes (76% vs. 52%, $p<0.0001$ )  A positive correlation between being a female with type 1 diabetes and a higher perception of diabetes-related stigma was found ( $p<0.0005$ ).  The impact of diabetes stigma on all aspects of life for type 1 and type 2 was significantly* associated with a higher A1C (>7 vs. ≤7%) and poorer self-reported blood glucose control (uncontrolled vs. controlled). *Significance rate not reported	Parents answered on behalf of their children, and self-reported measures were used, which could bias results.
Brazeau et al. (2018)	380 participants (14-24 years)	Determine the	Cross-sectional study.	Stigma prevalence was 65.5% (95% CI 60.7-70.3) across 380 respondents.	Mixture of direct measures and

Canada <sup>17</sup>	<p>HbA1c was only available for 312 participants</p> <p>31.1% Male 67.6% Female 1.3% Other</p> <p>57.9% participants were on an insulin pump</p> <p>Average diabetes duration: 9.6 years</p>	<p>prevalence of stigma in adolescents with type 1 diabetes and its associations with glycaemic control.</p>	<p>Stigma was assessed using the Barriers to Diabetes Adherence in Adolescence Questionnaire (BDA), 12 closed-ended questions, and open-ended questions.</p> <p>Other measures used: Self-Efficacy for Diabetes Self-Management measure (SEDM).</p> <p>Poor diabetes management =HbA1c*&gt;9% and/or at least 1 severe hypoglycaemic episode in the last year.</p>	<p>Stigma was associated with a 2-fold higher odds of poor glycaemic control (OR 2.25, 95% CI 1.33-3.80 adjusted for age, sex, and type of treatment).</p> <p>HbA1c &gt; 9% (75/mmol/mol) was 3-fold greater (OR 3.05, 95% CI 1.36-6.86) and severe hypoglycaemia in the previous year was 2-fold greater (OR 1.86, 95% CI 1.05-3.31) in those with versus without stigma.</p> <p>Being stigmatised was associated with a 0.9 (95% CI -1.3 to -0.6) lower SEDM score, which corresponds to an approximately 0.5 SD lower score.</p>	self-reported HbA1C measures.
Hansen et al. (2020)  Denmark <sup>24</sup>	<p>1594 adults (mean age=49)</p> <p>50% Female</p> <p>Average Diabetes duration: 25 years</p> <p>17% of participants were</p>	<p>Investigate the relationship between diabetes stigma and diabetes outcomes with adults living with</p>	<p>Cross-sectional study.</p> <p>Measures used: The Danish version of the Type 1 Diabetes Stigma Assessment Scale (DSAS-1 DK) was used to measure stigma.</p>	<p>All stigma subscales significantly predicted higher HbA1c.</p> <p>For a 1-unit (score points) increase in the identity concern score of the adjusted model*, a .11 unit increase in HbA1c is predicted (95% CI 0.02-0.21, <math>R^2=0.05</math>, <math>p&lt;0.05</math>).</p>	<p>Potential response bias: nonrespondents to the survey differed slightly, but significantly in terms of age, diabetes duration, complication status, and</p>

	on an insulin pump	type 1 diabetes.	Diabetes management was measured using HbA1c.	<p>For a 1-unit increase in the blame and judgement score of the adjusted model*, a .28 unit increase in HbA1c is predicted (95% CI 0.16-0.40, <math>R^2 = 0.06</math>, <math>p &lt; 0.001</math>).</p> <p>For a 1-unit increase in the treated differently score of the adjusted model*, a .28 unit increase in HbA1c was predicted (95% CI 0.14-0.42, <math>R^2 = 0.06</math>, <math>p &lt; 0.001</math>).</p> <p>*Adjusted for gender, age, diabetes duration, and education attainment.</p>	glycaemic outcomes, which could impact on results.
Sürücü et al. (2020) Turkey <sup>18</sup>	<p>80 adolescents (ages 10-18)</p> <p>Mean diabetes duration was not reported</p> <p>Participants on an insulin pump: none-was an exclusion criteria in the study</p>	<p>Investigate stigmatisation , sociodemographic/diabetes-related characteristics and parent-related characteristics as predictors of a negative perception of insulin treatment in adolescents with type 1 diabetes.</p>	<p>Cross-sectional correlation design.</p> <p>Stigmatisation measured using Barriers to Insulin Treatment Scale (BIT).</p> <p>Diabetes management was measured using HbA1c and the Appraisal of Insulin Therapy Scale (ITAS).</p>	<p>A statistically significant positive relationship was found between a negative perception of insulin treatment and stigmatisation (<math>r = .34</math>, <math>p = 0.002</math>) and between adolescents informing others about their illness (<math>r = .29</math>, <math>p = .009</math>) and preferring to use insulin alone when in public places (<math>r = .25</math>, <math>p = 0.027</math>).</p>	<p>BIT and ITAS have only been validated with type 2 diabetes.</p> <p>Possible recruitment bias as all 80 participants were residing in an in-patient hospital.</p>

Mahdilouy & Ziaeirad (2021)  Iran <sup>25</sup>	135 participants (ages 18-40)  42.2% Female 57.8% Male  Average diabetes duration: 12.77 years  Participants on an insulin pump: Not specified	Investigate the relationship between perceived social stigma and diabetes self-care in Iranian participants.	Cross-sectional study.  The Type 1 Diabetes Stigma Assessment Scale (DSAS-1) was used to measure stigma.  Diabetes management was measured using the Summary of Diabetes Self-Care Activities Questionnaire (SDSCAQ) and HbA1c.	No significant relationship was observed between perceived social stigma and the DSC activities ( $r = -0.043, p > 0.05$ ).  A significant positive relationship was observed between HbA1c and stigma ( $r = 0.169, p = 0.05$ ).	Self-reported measures which could potentially lead to bias.
Persky (2021)  Unknown (Involved online recruitment with no restrictions noted) <sup>25</sup>	177 participants (mean age=40.39)  78% Female  Average diabetes duration: Not specified  Participants on an insulin pump: Not specified	Investigates the relationships among casual attributions, internalised stigma, and self-blame with health and life satisfaction consequences with type 1 and type 2 diabetes.	Cross-sectional study.  Stigmatisation was measured using the Universal Measure of Bias, negative attitudes, and distancing subscales.  Diabetes management was measured using the Diabetes Self-Management Questionnaire (DSMQ).  Symptoms were reported using a shortened version of the Diabetes Symptom Checklist-Revised.	Behavioural causal attributions were positively associated with internalised stigma: negative attitudes ( $\beta = .13, p < .05$ ) and self-blame ( $\beta = .140, p < .01$ ).  Individuals who experienced self-blame expressed poorer self-care ( $\beta = -.248, p < .01$ ).  Self-care was negatively associated with symptoms ( $\beta = -.93, p < .01$ ).  Symptoms were negatively associated with life satisfaction ( $\beta = -.36, p < .01$ ).	Does not specify whether participants were on pumps or diabetes duration.

Ingram (2022) Australia <sup>19</sup>	76 adolescents with type 1 diabetes, mean age 14.3 years (12-18 years old)  53.6% Female 47.4% Male  Average diabetes duration: 6.2 years  71.1% of participants were on an insulin pump	To explore the prevalence of diabetes stigma in adolescents with type 1 diabetes, explore differences in reports of stigma compared to adults, and investigate if stigma is associated with glycaemic control in adolescents.	Cross-sectional study.  Stigmatisation was measured using the Type 1 Diabetes Stigma Assessment Scale (DSAS-1).  Diabetes management was measured using HbA1c.	98.7% of participants related to at least one item on the stigma scale.  The addition of the ‘treated differently’ scores resulted in a significant increase in the predictive capacity of the model $\Delta F(1, 67) = 8.76, p = .004, \Delta R^2 = .102$ .  The addition of the ‘blame and judgement’ subscales significantly increased the predictive capacity of the model $\Delta F(1, 68) = 3.74, p = .048, \Delta R^2 = .051$ , meaning that Blame and judgement scores were associated with higher HbA1c levels.  The addition of the ‘identity concerns’ subscale resulted in a significant increase in the predictive capacity of the model $\Delta F(1, 69) = 4.38, p = .040, \Delta R^2 = .053$ , indicating that higher treated different scores were associated with higher HbA1c levels.	Sample size and statistical power was lower than desired.
Eitel et al. (2023) United States <sup>26</sup>	1,255 respondents with Type 1 Diabetes (10-24.9 years)  53.2% Female 46.8% Male	To examine the association between diabetes stigma and HbA1c.	Cross-sectional. Multivariable linear modelling.  Stigmatisation was measured using the SEARCH 4 diabetes-related stigma survey.	Higher diabetes-related stigma scores were associated with higher HbA1c ( $\beta = -1.41, p < 0.0001$ )  Where sex was female, this was associated with a 1.96 point higher diabetes-related stigma score compared to where sex was male ( $p < 0.0001$ ).	Possible self-reporting bias for some variables.  SEARCH 4 diabetes-related stigma survey is not validated.



	<p>Average diabetes duration: 11.1 years</p> <p>Participants on an insulin pump: specific number not specified in article but was factored in analysis and found to not be correlated with stigma</p>		<p>Diabetes management was measured using HbA1C, presences of complications and diabetic ketoacidosis (DKA) episodes.</p>	<p>When adjusted for HbA1c, the presence of a DKA episode (<math>\beta = 1.61</math>, <math>p = 0.0003</math>) and a severe hypoglycaemia episode (<math>\beta = 1.60</math>, <math>p = 0.002</math>) in the past year was associated with higher diabetes-related stigma scores.</p> <p>Independent of HbA1c, the presence of retinopathy (<math>\beta = 1.94</math>, <math>p = 0.0002</math>) and nephropathy (<math>\beta = 1.16</math>, <math>p = 0.04</math>) were associated with higher diabetes-related stigma scores.</p> <p>No significant association was found between diabetes-related stigma scores and the use of an insulin pump or CGM (<math>\beta = -0.23</math>, <math>p = 0.4897</math>)</p>	
<p>Hamano et al. (2023)</p> <p>Japan <sup>27</sup></p>	<p>109 participants (average age 58.3 years)</p> <p>56.8% Female 43.1% Male</p> <p>Average diabetes duration: 25.5 years</p> <p>Participants on an insulin pump: Not specified</p>	<p>To examine the association between self-stigma and HbA1c in Japanese people with type 1 diabetes.</p>	<p>Cross-sectional study.</p> <p>Stigmatisation was measured using the 9-item shorter. Japanese version of the Type 1 Diabetes Stigma Assessment Scale (DSAS-1)</p> <p>Diabetes management was measured using average HbA1c.</p>	<p>After adjusting for age, sex, employment status, BMI, duration of diabetes, and insulin secretion, the positive association between self-stigma and HbA1c remained significant (<math>\beta = 0.05</math>, 95% CI 0.01-0.08, <math>p = 0.009</math>).</p>	<p>Because of the cross-sectional nature, causality cannot be proven.</p> <p>Small sample size.</p> <p>The short version of the Self-Stigma scale has only been validated with the type 2 population.</p>

Qualitative Studies					
Abdoli et al. (2013) Iran <sup>28</sup>	33 participants (ages 20-37)  21 Females 12 Males Diabetes duration: 2-24 years  Participants on an insulin pump: not specified	To explore the relationship between stigma and type 1 diabetes in young people.	Content Analysis	Participants attempted to hide their diabetes in fear of stigma. This included not injecting in public places and avoiding insulin injections when they could not find somewhere private to inject.	
Balfe et al. (2013) Ireland <sup>15</sup>	35 young adults (ages 23-30)  29 Females 6 Males  Average diabetes duration: 11.5 years  26.5% participants were on an insulin pump	To identify causes of diabetes distress in a sample of young adults with type 1 diabetes.	Thematic Analysis	12 young adults described feeling self-conscious about their diabetes and its management.  Individuals who had strong stigma-related perceptions reported to avoid activities that they felt would highlight or reveal their diabetes to others. This included the wearing of devices or joining support groups,	Participants were recruited from Facebook, which could have led to a biased sample due to targeted recruitment.

<p>Browne et al. (2014)</p> <p>Australia<sup>29</sup></p>	<p>27 adults (ages 20-68)</p> <p>15 Females 12 Males</p> <p>Average diabetes duration: 15 years</p> <p>59% participants were on an insulin pump</p>	<p>Explore experiences of diabetes-related stigma from the perspective of adults with type 1 diabetes.</p>	<p>Thematic Analysis</p>	<p>Stigma had an impact on non-disclosure (23/27 participants); most notably in the workplace.</p> <p>Effect on management: “Participants made inconvenient and elaborate plans to be able to carry out necessary self-management activities without having to do it in public. i.e., injecting in toilet cubicles”</p> <p>Delaying essential self-management tasks.</p>	<p>Participants were recruited from a diabetes association mailing list. Those recruited may be more engaged in their diabetes care and aware of the issues than the general population.</p>
<p>Commissariat et al. (2016)</p> <p>United States <sup>20</sup></p>	<p>40 adolescents (ages 13-20)</p> <p>47% Female 53% Male</p> <p>Average diabetes duration: 6.87 years.</p> <p>68% participants were on an insulin pump</p>	<p>Explore adolescents’ views on the experience of living with diabetes and how living with type 1 diabetes affects self-concepts.</p>	<p>Thematic analysis</p>	<p>Some participants who felt stigmatised by their diabetes in social situation, felt it interrupted their self-management plans. Participants reported pretending they did not have diabetes and one participant reported that they removed their pump to avoid stigmatisation.</p>	<p>Study was conducted whilst participants were waiting for a medical appointment which may have influenced responses.</p>

<p>Elissa et al. (2017) Palestine <sup>23</sup></p>	<p>10 children (ages 8-16) with type 1 diabetes and their parents</p> <p>50% Female 50% Male</p> <p>Average diabetes duration not specified between less than one year and more than five</p> <p>Participants on an insulin pump was not specified</p>	<p>Explore experiences of daily life in children with type 1 diabetes.</p>	<p>Content Analysis</p>	<p>Stigmatisation led to hindered self-management through concealment and secrecy.</p> <p>Children and adolescents reported not adhering to treatment regimens to appear 'normal'. It was also reported that children refused significant self-care activities in public to avoid being rejected or judged by others.</p>	<p>Sampling was based on purposive selection of participants ensuring that participants who took part experienced stigma.</p>
<p>Nishio &amp; Chujo (2017) Japan <sup>30</sup></p>	<p>24 adult patients (29-66 years old)</p> <p>19 Females 5 Males</p> <p>Average diabetes duration not reported. Range between 3-28 years</p>	<p>Examine stigma and coping strategies of people living with type 1 diabetes.</p>	<p>Qualitative semi-structured interviews.</p>	<p>Stigma resulted in participants concealing their diabetes as a way of coping with diabetes stigma which included not taking insulin in public.</p>	<p>Method used for analysis is unclear.</p>

	Participants on an insulin pump was not specified				
Jeong et al. (2018)	14 young adults (ages 20-34)	Explore health-related stigma among young adults with type 1 diabetes	Content analysis	Young adults reported a high degree of stigma in their daily lives which negatively influenced their self-management of diabetes. Stigma led to delaying blood glucose monitoring and insulin dosing. Participants hid management from peers, family members, and the public.	Location of participants is not specified.
Unknown <sup>16</sup>	9 females 5 males  Average diabetes duration: 13.1 years  78.6% participants were on an insulin pump	using qualitative descriptive methods in focus groups.			
Momani (2022)	25 adolescents (ages 10-19)	To better understand barriers that influence self-management.	Constructive grounded theory.	Stigma led to individuals not disclosing their diabetes to people outside the family which makes self-management tasks more difficult.  System-level barriers were identified such as participants not being allowed to leave the classroom when they needed to engage with self-management tasks (i.e., inject insulin).	Social and cultural factors as well as public policy may not be generalisable between Jordan and other countries.  Unclear if system-level barriers are due to stigma or education.
Jordan <sup>21</sup>	16 Females 9 Males  Average diabetes duration: Not specified  Participants on an insulin pump were not specified				

Mencher et al. (2022) United States <sup>22</sup>	19 Black adolescents (mean age 15.8)  58% Female  Average diabetes duration: 6.2 years  28% participants were on an insulin pump	Qualitative study to understand how Black adolescents and their parents make decisions regarding methods of diabetes management.	Thematic analysis.	Stigma presented as a barrier to uptake on diabetes devices (DD). Adolescents were concerned with being stigmatised due to the visibility of DDs. One participant stated they stopped using their pump as they got bullied. It was felt that DDs would draw further attention to 'being different', intersecting with their status as a Black adolescent in a white majority community.	Participants were from a single centre, meaning findings might not be representative of other areas.
<b>Mixed-Method Studies</b>					
Hakkarainen et al. (2018) Finland <sup>31</sup>	688 employees with type 1 diabetes (ages 18-44) for the survey*  46.5% Female 53.5% Male  Diabetes Duration: 0 to 16+ years  Participants on an insulin pump were not specified	To explore the possible reasons for concealing type 1 diabetes at work.	Mixed-methods study design. Cross-sectional survey and semi-structured interviews with 20 participants.  Diabetes management was measured by HbA1c.	Not disclosing T1D to the extended family (OR 5.24, 95% CI 2.06-13.35, $p = 0.001$ ), feeling an outsider at work (OR 2.47, 95% CI 1.58-3.84, $p < 0.001$ ), being embarrassed by receiving special attention at work (OR 1.99, 95% CI 1.33-2.96, $p = 0.001$ ) and neglecting treatment at work (OR 1.59, 95% CI 1.01-2.48, $p = 0.044$ ) were all associated with concealment of T1D from colleagues.  The youngest age group of 18–24 years were more likely to conceal their T1D from their line managers than the older age groups during their working career ( $p = 0.011$ ). Not disclosing T1D to the extended family (OR 4.41 (95% CI 1.72 to	Self-reported measures were used, and biases could occur in recall in measures such as HbA1c.  Response rate was 49%. Small nonrespondent bias for gender distribution.

\*20 participants  
took part in semi-  
structured  
interviews

11.32,  $p = .002$ ), feeling like an outsider at work (OR 2.51, 95% CI, 1.52-4.14,  $p < 0.001$ ) and being embarrassed by receiving special attention at work (OR 1.81, 95% CI, 1.13-2.91,  $p = 0.014$ ) were associated with concealment of T1D from line managers.

From the interviews, five main themes related to concealment emerged, expressing fears related to the consequences of telling: (1) being perceived as weak, (2) job discrimination, (3) unwanted attention, (4) being seen as a person who uses their T1D for seeking advantages and (5) losing privacy. Having regular meal breaks, measuring glucose levels, taking injections, and visiting the doctors were seen as difficult for those who try to conceal their condition.

\*HbA1c is the average blood glucose (sugar) level for the last two to three months. An ideal HbA1c level for someone with diabetes is 44mmol/mol (6.5%) or below.

## *Measures*

### *HbA1c*

Measurements varied across studies. Across the nine quantitative studies and the one mixed method study, all studies but one<sup>25</sup> reported the HbA1c levels of participants. There were differences in how this information was gathered. For some studies, HbA1c was taken from a recent blood sample; some utilised medical records and others had participants self-report their HbA1c. The latter is potentially problematic because it is subject to self-report bias, and not all participants may have been tested recently. One study<sup>17</sup> allowed for some participants to self-report their HbA1c when they were unable to obtain a collected sample, which could have impacted findings due to inconsistencies between data.

Whilst HbA1c can indicate how successfully an individual is managing their diabetes, it is not a direct measure of diabetes management as it can be influenced by additional factors such as time since diagnosis, time spent in hypoglycaemia, infection, or illness. Only two quantitative studies included hypoglycaemic episodes in their results<sup>17,26</sup>. Three studies focused solely on the measurement of HbA1c<sup>19,21,24</sup> and did not use any additional outcomes to measure diabetes management. One study also mentioned the correlation between complications and stigma<sup>26</sup>. What was considered a high HbA1c varied. One study<sup>6</sup> deemed poor diabetes management to be measured by a HbA1c>7%, whilst another study listed a HbA1c>9% to be indicative of poor diabetes management.

### *Self-Management Behaviours*

Some studies used additional questionnaires to measure diabetes management. Some of the questionnaires used included the Appraisal of Insulin Therapy Scale<sup>18</sup> ( $n=1$ ), Diabetes Self-Care Activities measure<sup>32</sup> ( $n=1$ ), Self-efficacy in Diabetes Management questionnaire<sup>17</sup>



( $n=1$ ), and the Diabetes Self-Management Questionnaire<sup>25</sup> ( $n=1$ ). One study<sup>6</sup> utilised their own online survey that included questions on aspects of diabetes treatment, behaviours, and attitudes concerning diabetes management. An additional study developed a survey where respondents were asked specific questions about concealing their diabetes<sup>31</sup>. A further discussion on the validation of measures is provided below in study quality.

### *Stigma*

Measures for stigma also varied and included the stigma subscales within the Barriers to Diabetes Adherence Scale<sup>17</sup> ( $n=1$ ), the Barriers to Insulin Treatment scale<sup>18</sup> ( $n=1$ ), the Type 1 Diabetes Stigma Assessment Scale<sup>19,24,27,32</sup> ( $n=4$ ), SEARCH 4 Diabetes-related Stigma Survey<sup>26</sup> ( $n=1$ ), and the Universal Measure of Bias, Negative Attitudes and Distancing Subscales<sup>25</sup> ( $n=1$ ). One study<sup>6</sup> utilised its own online survey that was used to measure stigma.

### *Study Quality and Risk of Bias*

The MMAT<sup>14</sup> was used to assess the quality of the methodology of each included study. The MMAT contains a checklist of questions for each study design. Each question can be answered with either a yes, no or cannot tell. The most updated version does not recommend using an overall score as this can be problematic as not all missed qualities will be of equal weight<sup>33</sup>. Instead, it is recommended to utilise the MMAT as a tool to understand what areas to report on.

The MMAT highlighted two main areas of concern for the quantitative and mixed-method studies. One area of concern regarded the appropriateness of measures. Four of the nine studies were marked as ‘no’ regarding the appropriateness of measures. In two studies<sup>6,26</sup>, measures were created for the study and, to the knowledge of the authors, had not

been validated prior to the study. In another two studies<sup>18,27</sup>, measures used had been validated with the type 2 population only. The second area of concern was the risk of nonresponse bias. Only one quantitative study<sup>24</sup> and one mixed-method study<sup>31</sup> reported their risk of nonresponse bias. Notably, the quantitative study<sup>24</sup> found that non-respondents to the survey differed slightly, but significantly in terms of age, diabetes duration, complication status, and HbA1c which could impact on results.

All qualitative studies performed well against the methodological quality criteria. Only one study<sup>30</sup> was marked with a 'cannot tell' for question 1.3 regarding how the data was analysed. This was because the approach used a coding procedure, but the methodology used was unclear. A further breakdown of the answers for each study can be found in the Appendix.

### *Main Findings*

Our systematic review yielded nineteen studies. All studies found that health-related stigma negatively impacts the management of type 1 diabetes. It was found that health-related stigma may act as a barrier to the uptake of diabetes technology, lead to non-disclosure and lead to avoidance of self-care activities in public. Amongst the included studies, there was heterogeneity between study designs and the measures within the studies.

### *Quantitative Studies*

All nine of the quantitative studies found a correlation between factors measuring stigma and diabetes management, whereby stigma negatively impacts diabetes management. All four studies<sup>19,24,27,32</sup> that utilised the Diabetes Stigma Assessment Scale (DSAS-1) and HbA1c found significant positive relationships. The DSAS-1 consists of three subscales: Being treated differently, blame and judgement, and identity concerns, which represent

different elements of felt and enacted stigma. Two of the four studies<sup>19,24</sup> that used this measure presented results with these subscales and found that each subscale was associated with an increase in HbA1c.

Only two studies<sup>17,26</sup> reported results on the association between stigma and hypoglycaemia. Eitel et al.,<sup>26</sup> reported that when adjusted for HbA1c, the presence of a diabetic ketoacidosis (DKA) event ( $p=.0003$ ) and a severe hypoglycaemic episode ( $p=0.002$ ) in the past year was associated with higher diabetes-related stigma scores. Brazeau et al.,<sup>17</sup> reported that the presence of a severe hypoglycaemia event was 2-fold greater (OR 1.86, 95% CI 1.05-3.31) in those with versus without stigma. In addition to reporting hypoglycaemic events, Eitel et al.,<sup>26</sup> also found positive associations between diabetes complications and stigma when controlling for HbA1c. The presence of retinopathy ( $p=0.0002$ ) and nephropathy ( $p=0.04$ ) were associated with higher diabetes-related stigma scores.

Few studies reported on the association between stigma and self-management tasks, with most studies focusing on HbA1c. However, most studies<sup>17,18,25</sup> that reported on self-management tasks found that stigma negatively impacted these behaviours. Sürücü et al.,<sup>18</sup> found a significant positive relationship between stigmatisation and adolescents informing others about their illness ( $r=.29, p=.009$ ) and preferring to use insulin alone when in public places ( $r=.25, p=0.027$ ). This indicates that when faced with stigmatisation, adolescents are more likely to conceal their diabetes, which could result in delayed self-care activities and poorer diabetes management. Interestingly, one study<sup>32</sup> found no significant association between perceived social stigma and diabetes self-care activities ( $r=-0.043, p > 0.05$ ). However, the study did find an association between HbA1c and stigma ( $r=0.169, p=0.05$ ). As the HbA1c measure was taken from medical records, it could be that the measure for diabetes self-care activities was prone to a self-report bias.

A significant limitation was the various outcome measures and variables used within the quantitative studies. It was difficult to directly compare results and assess how much other factors may impact diabetes management. Research on the concepts of *diabetes distress* and *diabetes burnout* has shown there are multiple contributing factors which can lead to higher HbA1c and reduced self-care<sup>34,35</sup>. Therefore, it becomes difficult to know how much of a direct effect stigma plays in reducing self-care without controlling for these other variables.

Despite these limitations, due to the consistency of the findings across studies, there appears to be a robust association. It is important to note that bi-directional effects could occur between stigma and HbA1c, as well as stigma and self-management behaviours. For example, when an individual is stigmatised, they may experience feelings of shame and a desire to hide their condition. This can result in decreased self-care in public, which can lead to higher HbA1c. Equally, individuals who struggle with diabetes management may, as a result, make their condition more noticeable by experiencing more hypoglycaemic events or added visible complications such as lower limb amputations and thus experience more shame.

### ***Qualitative Studies***

Qualitative studies provided additional context to the observed effects reported in the quantitative research by providing insight into how diabetes management is affected. Across the nine qualitative studies and one mixed-method study, themes covered the impact of stigma on the uptake of technology, non-disclosure leading to an avoidance of self-care in public, and the effect of stigma on systems.

### ***Concealment of Diabetes***

All qualitative studies described how individuals avoided disclosing their diabetes to varying degrees to prevent stigmatisation. In some instances, this meant not revealing to the people around them that they had type 1 diabetes, such as their employer, teachers, and peers<sup>15,16,20–22,29–31</sup>. In some cases, keeping their diabetes a secret meant individuals tended to avoid or delay activities that they felt would highlight or reveal their diabetes to others, including seeking help<sup>15,16</sup>, wearing diabetes tech<sup>15,20</sup>, and self-management tasks<sup>15,16,20,23,29,30</sup>.

Avoiding self-management tasks in public often meant individuals needed to make elaborate plans to check their glucose or inject<sup>28,29</sup>. This carried the risk that these essential self-management tasks could be delayed or avoided altogether. At least three studies reported that some participants would check their blood glucose and inject insulin in toilet cubicles, invoking feelings of shame and distress<sup>16,29,30</sup>. In some instances, individuals tried to escape the identity of having type 1 by pretending to be ‘normal’, resulting in a complete avoidance of self-management tasks when out with friends<sup>20</sup>. In a further study, two young adults shared that they were willing to put themselves at risk of hypoglycaemia to avoid embarrassment<sup>16</sup>.

### *Stigma and Technology*

While technology can remove the stigmatisation of injecting in public, it brings its own stigma. The visibility of diabetes technology may lead to additional stigmatisation as it makes the condition more visible. Studies reported that individuals would avoid activities showing their devices, such as swimming, or remove diabetes technology so that it would not be visible<sup>20,29</sup>. In one of these studies, it was reported that an individual removed their pump after they had been bullied and did not return to wearing it for at least two years<sup>20</sup>.

Stigma was also seen as a barrier to the uptake of technology. One study<sup>22</sup> found that Black adolescents were concerned with being stigmatised due to the visibility of diabetes technology. This was especially prevalent in adolescents who felt embarrassed by their condition and feared disclosure, as they thought the technology exposed their diabetes to others. They expressed concern that their friends may treat them differently or judge them negatively should they find out they were living with diabetes. The stigma experienced was further compounded by their experience of being a Black adolescent in a White majority community. They reported fear that the diabetes technology would draw further stigma to them 'being different', which pointed to a broader issue of *Intersecting Stigmas*<sup>36</sup>.

#### *Intersectional Stigma*

Intersectional stigma describes the combination of multiple stigmatised identities within a person or group<sup>36</sup>. Apart from one paper<sup>22</sup>, none directly investigated the impact of intersectionality in relation to ethnicity or within communities such as the LGBTIQ+. Some studies highlighted differences in sex with the stigmatisation of being female intersecting with having diabetes<sup>23,28</sup>. A further study indicated that females were more open about discussing their experience and more descriptive than their male counterparts<sup>20</sup>. Therefore, there could be stigmas for the male sex, inhibiting the sharing of difficulties.

#### *Differences between Ages*

Both, quantitative and qualitative studies covered different age groups, including children, adolescents, young adults, adults, and older adults. However, no qualitative studies focused on the experience of older adults living with type 1 diabetes, revealing a gap in the existing literature. While a quantitative study<sup>5</sup> did include older adults, it revealed that this

age group still faces stigmatisation, underlining the need for further research to comprehend this experience better.

Due to variances between studies, we could not determine if the effects of stigma change with age. However, research has shown that the perception of stigma varies by age and that youth (ages 14-24) experience the highest stigma perception compared to middle-aged adults and seniors<sup>37</sup>.

### *Differences between Cultures*

The review highlighted that stigma and its relationship with type 1 diabetes occurs across cultures. Across this systematic review, eleven different areas were included in the research: Iran, Ireland, Australia, United States, Canada, Palestine, Japan, Finland, Denmark, Turkey, and Jordan. Stigma was shown to be experienced cross-culturally.

The differing cultural beliefs, as well as differing social policies, may mean that pressure to conceal diabetes is heightened. In Jordan, the development of diabetes was associated with punishment for previous sins<sup>21</sup>. A further study in Palestine found that women experienced additional social pressures to hide their diabetes due to the risk of appearing as a burden to potential partners both economically and socially<sup>23</sup>. One study in Iran found similar results, with women reporting additional stigma and barriers compared to men<sup>28</sup>. One woman said she did not inject her insulin in front of her husband's family due to fear of what they would think<sup>28</sup>. Varying healthcare systems also meant the cost of living with diabetes created additional barriers and meant that individuals may be more likely to be stigmatised<sup>23</sup>.

### *Impact of Stigma on Systems*

Some studies commented on the blame that individuals living with diabetes experienced from their healthcare professionals and caregivers, which in some instances resulted in further stigmatisation<sup>16,29</sup>. One participant reported feeling shamed by their healthcare team<sup>16</sup>, resulting in him wanting to manage his diabetes alone. To avoid additional stigma and shame, individuals may avoid attending appointments with professionals who could support them or avoid seeking support from others around them.

Some studies spoke about the fear of disclosing their diabetes to their workplace, fearing they would be treated differently or lose their jobs<sup>31</sup>. Educational settings were also seen as a barrier, as some children could not leave the classroom to inject insulin<sup>21</sup>. However, it was unclear if this was due to discrimination or a lack of understanding of the condition.

### **Limitations**

Whilst the studies seem to indicate that stigma has a negative impact on diabetes outcomes and self-management tasks, the included papers varied in terms of their focus, sample, and methodology, which made it challenging to compare the research and to draw firm conclusions. In addition to this, all quantitative studies included in the paper were correlational, so causality cannot be determined.

A meta-analysis may have offered a more robust synthesis of the existing evidence. However, due to the limited quantitative studies and the heterogeneity between measures and outcomes, a meta-analysis was not considered appropriate.

Another limitation involves the scope of the topic area. Stigma can impact many areas of diabetes, including management, but also on quality of life. The current study limited results to only studies that directly spoke of the relationship between diabetes management



and stigma. This means that papers including some indirect factors may have been excluded. Whilst the authors acknowledge that many factors affect an individual's ability to manage their diabetes, it would not have been feasible to include these papers within the scope of this review.

## **Conclusions**

Despite the limitations, this review was the first known to the authors that provided a systematic review of the literature on the impact of stigma on diabetes outcomes and self-management behaviours in type 1 diabetes that conformed to PRISMA guidelines. Nineteen studies were included and comprised of a combination of quantitative, qualitative, and mixed-methods studies. An additional benefit of utilising a mixed methods approach was the complementary effect of using two different types of data had in creating a more holistic picture of understanding a person's experience. All nineteen studies reported some effects of varying degrees on the impact of stigma on type 1 diabetes. A significant strength of this study is the wide range of countries we could draw from. Despite cultural differences, stigma appears to impact on the management of diabetes, indicating that this concept is a global phenomenon.

Even though all quantitative studies were correlational, there was a consistent negative relationship between stigma and treatment outcomes across all nine studies. Qualitative studies also helped to understand the effects observed in the quantitative studies. They highlighted that stigma can affect the uptake of technology, self-care activities, help-seeking, disclosure, and system-wide barriers. Due to the limitations of the correlational designs used in this study, it is proposed that future research in this area looks at longitudinal studies, which could contribute more to the evidence base. This would enable a further examination of the relationship found alongside potential confounding variables.

Across the studies, ages, diabetes duration, and technology use varied, and not all studies reported all demographics. Regardless, all studies reported an effect between stigma and diabetes management, indicating that whether an individual is a child or young adult, on an insulin pump or taking insulin injections, stigma is still experienced. However, due to the variance between study designs and measures, we cannot determine if there was a difference between some groups, such as with age or technology use. Some of the studies reviewed did show an increased likelihood of experiencing stigma when an individual's sex was female.

The impact of intersectional stigma was also observed, but there is a need for additional research within this area. Stigmatised characteristics are often researched individually, yet many marginalised individuals are experiencing a multitude of various stigmas put on them simultaneously<sup>36</sup>. Professionals around an individual must understand that individuals living with diabetes may be experiencing additional pressures and how this would impact their management of diabetes.

The findings of this search have also shown a need to consolidate the measures used for both stigma and self-management behaviours. Not only were different questionnaires used, but how treatment adherence was measured also varied with some studies using HbA1c, efficacy, or self-care behaviours. Future reviews could look at consolidating information for what measures exist for either of these variables and understanding how treatment adherence can be measured so that research could be more standardised.

Lastly, future research should look at interventions to help individuals experiencing stigma. As mentioned in this review, the issue of addressing stigma is not solely with the individual living with diabetes but with that of the broader systems around the individual. Likely, both individual interventions to help support the person living with type 1 diabetes and support on a systemic level would be needed. For example, when technology was less

visible, easy to hide, and less complicated, it was seen as a facilitator in managing diabetes<sup>22</sup>. Interventions that involve improving access to technology and making it less visible would be influential in helping individuals feel less stigmatised.

Additionally, strategies to help break down stigma should be offered to healthcare professionals, parents, and the public. In one study, individuals reported they felt angry at the lack of positive media representation of diabetes<sup>15</sup>. There is power in representation within the media, and some public figures have increasingly challenged stigma through the visibility of diabetes devices<sup>9</sup>. This representation has the potential to raise awareness and destigmatise diabetes on a systematic level. More recently, a campaign to proactively target diabetes stigma and discrimination has been launched<sup>38</sup>. While it is too early to assess the impact of this campaign, it is hoped that this, along with other initiatives, will affect positive change by highlighting and thereby starting to address the issue of stigma in diabetes.

### **Funding**

None. This review was undertaken as part of a doctoral research project.

### **Conflicts of Interest**

There are no potential conflicts of interest to declare.

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## Appendix A. PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
<b>TITLE</b>			
Title	1	Identify the report as a systematic review.	4
<b>ABSTRACT</b>			
Abstract	2	Provide a structured summary including, as applicable, background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number	2
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	3-4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	4
<b>METHODS</b>			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	5-6
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	5
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	5
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	5-6
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	6
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	6

	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	8
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	8-19
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	5-6
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	5-6
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	6
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	6
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	6
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	8-19
<b>RESULTS</b>			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	7
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	5-6
Study characteristics	17	Cite each included study and present its characteristics.	8-19
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	22
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	8-19
	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	8-9; 34



Results of syntheses	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	8-19
<b>DISCUSSION</b>			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	23
	23b	Discuss any limitations of the evidence included in the review.	27-28
	23c	Discuss any limitations of the review processes used.	27-28
	23d	Discuss implications of the results for practice, policy, and future research.	28-30
<b>OTHER INFORMATION</b>			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	5
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	5
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	30
Competing interests	26	Declare any competing interests of review authors.	30
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A
<b>Section and Topic</b>	<b>Item #</b>	<b>Checklist item</b>	<b>Location where item is reported</b>
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Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	5-6
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	5
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Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	6
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Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	8-19
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	5-6
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	5-6
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	6

	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	6
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	6
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	8-19
<b>RESULTS</b>			
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	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	8-19
<b>DISCUSSION</b>			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	23

	23b	Discuss any limitations of the evidence included in the review.	27-28
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Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	30
Competing interests	26	Declare any competing interests of review authors.	30
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

## Appendix B: MMAT Checklist

\*All studies answered Yes to questions S1. “Are there clear research questions?” And S2. “Do the collected data allow to address the research questions?”.

### Quantitative studies

	4.1 Is the sampling strategy relevant to address the research question?	4.2. Is the sample representative of the target population?	4.3. Are the measurements appropriate?	4.4. Is the risk of nonresponse bias low?	4.5 Is the statistical analysis appropriate to the research question?
Liu et al. (2017)	Yes	Yes	No	Cannot Tell	Yes
Brazeau et al. (2018)	Yes	Yes	Yes	Cannot Tell	Yes
Hansen et al. (2020)	Yes	Yes	Yes	No	Yes
Sürücü et al. (2020)	Cannot Tell	Cannot Tell	No	Cannot Tell	Yes
Mahdilouy & Zierirad (2021)	Yes	Yes	Yes	Cannot Tell	Yes
Persky (2021)	Yes	Cannot Tell	Yes	Cannot Tell	Yes
Ingram et al. (2022)	Yes	Cannot Tell	Yes	Cannot Tell	Yes
Eitel et al. (2023)	Yes	Yes	No	Cannot Tell	Yes
Hamano et al. (2023)	Yes	Yes	No	Cannot Tell	Yes

### Qualitative studies

	1.1. Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
Abdoli et al. (2013)	Yes	Yes	Yes	Yes	Yes
Balfe et al. (2013)	Yes	Yes	Yes	Yes	Yes
Browne et al. (2014)	Yes	Yes	Yes	Yes	Yes
Commissariat et al. (2016)	Yes	Yes	Yes	Yes	Yes
Elissa et al. (2017)	Yes	Yes	Yes	Yes	Yes
Nishio & Chujo (2017)	Yes	Yes	Cannot Tell	Yes	Yes

Jeong et al. (2018)	Yes	Yes	Yes	Yes	Yes
Momani (2022)	Yes	Yes	Yes	Yes	Yes
Mencher et al. (2022)	Yes	Yes	Yes	Yes	Yes

### Mixed-Method Studies

	1. Is there an adequate rationale for using a mixed methods design to address the research question?	2. Are the different components of the study effectively integrated to answer the research question?	3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
Hakkarainen et al. (2018)	Yes	Yes	Yes	Yes	Yes

## **Chapter 2: Empirical Paper**

## **Turning the T1DE: Recovery Factors in Type 1 Disordered Eating**

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This paper has been prepared in accordance with the submission guidelines for *Psychology & Health*:

<https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=gps>

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## Turning the T1DE: Recovery Factors in Type 1 Disordered Eating

**Objective:** T1DE (type 1 disordered eating) is an acronym used to describe eating disorder behaviours in individuals living with type 1 diabetes. This study aimed to develop a recovery model for individuals living with T1DE.

**Design:** Thirteen people met the study criteria and participated in semi-structured interviews. Interviews were analysed using constructivist grounded theory.

**Results:** A theory of recovery was developed by data grounded in the narratives of people with lived experience. Five major categories were constructed and linked to the process of recovery. These are presented as the 5Rs of recovery: (1) readiness to change, (2) roadblocks, (3) recovery factors, (4) risk factors, and (5) relapse. Underpinning each category is a combination of biological, psychological, social, and systemic factors.

**Conclusion:** Our findings propose a theory on the process of recovery and present common recovery factors. The presented model of recovery could be used as a formulation tool to help individuals living with T1DE and their teams. Those working with this population may want to consider how their services can facilitate any of the listed recovery factors as well as limit the barriers mentioned.

**Keywords:** type 1 diabetes, disordered eating, grounded theory, recovery, recovery factors, type 1 disordered eating.

## Introduction

Type 1 diabetes is a lifelong condition in which the pancreas produces little to no insulin, the hormone needed to allow glucose to enter cells and produce energy (Wilkinson et al., 2017). Those living with type 1 diabetes must self-manage their condition, which involves significant lifestyle changes like carbohydrate counting at every meal, monitoring of blood glucose levels throughout the day, and daily insulin injections. Research has shown that those living with type 1 have an increased risk of developing psychological issues such as eating disorders compared to individuals without diabetes, due in part to the additional stresses

caused by the care tasks listed above (Goebel-Fabbri, 2009; Hanlan et al., 2013).

Differing definitions exist behind the terms ‘eating disorders’ and ‘disordered eating’. There is no consensus on what terminology to use within the type 1 diabetes literature (Broadley et al., 2020; Partridge et al., 2020). The term *eating disorder* refers to the psychiatric labels presented in the Diagnostic and Statistical Manual of Mental Disorders (*Diagnostic and Statistical Manual of Mental Disorders: DSM-5.*, 2013) and the International Classification of Diseases: ICD-11 (World Health Organization, 2019). These can include difficulties involving extreme food restriction (anorexia nervosa) to overeating and unhelpful compensatory behaviours (bulimia nervosa and binge eating disorder). Individuals who do not meet the criteria for either may receive a diagnosis of ‘eating disorder; not otherwise specified’ (Hanlan et al., 2013).

These diagnostic labels, however, struggle to capture the difficulties specific to those living with type 1 diabetes, where disordered eating presentation may look significantly different due to the unique role of insulin. Without a regular and adequate insulin dose, a person with diabetes can induce a state of hyperglycaemia (high blood glucose) and ketoacidosis, where the body breaks down fat cells to gain energy, thereby causing weight loss (Hall et al., 2021). When people with diabetes become aware of this, they may underdose or entirely omit their insulin to lose weight. This behaviour poses significant risks in the form of long-term health complications caused by chronic high blood glucose levels and significant acute risks in the form of diabetic ketoacidosis, a dangerous and often life-threatening condition (Hall et al., 2021). Disordered eating behaviours may also occur when a person with diabetes is in a state of hypoglycaemia (low blood glucose), as biologically, they are driven to eat significant amounts to rebalance their blood glucose levels, often resulting in dysregulated binge eating behaviours (Broadley et al., 2020; Goebel-Fabbri, 2009).

The DSM-5 classifications for eating disorders do not include diabetes-specific

elements such as insulin omission within the diagnostic criteria (Broadley et al., 2020). Therefore, a person with type 1 diabetes who restricts their insulin may not fulfil diagnostic criteria for an eating disorder diagnosis even though they risk acute and life-threatening complications. There are situations where individuals may face difficulties in obtaining support and treatment from conventional eating disorder services. However, initiatives are underway to enhance accessibility by revising clinical guidelines. The National Institute for Clinical Excellence (NICE, 2020) has recently revised its guidelines pertaining to individuals living with diabetes who present with eating disorder behaviours and proposes that eating disorder teams and diabetes teams should work together to address both mental and physical health concerns. Recently, the ICD-11 has now included insulin omission within its criteria for *bulimia nervosa* (World Health Organisation, 2019).

The term *disordered eating* typically refers to symptoms that are not severe or frequent enough to be considered a diagnosable eating disorder. It includes all behaviours related to weight loss and binge eating (Pereira & Alvarenga, 2007). Given the aforementioned high risk of life-threatening complications as a direct result of this behaviour, *disordered eating* as a diagnostic term does not seem to capture the severity of the condition in this population. Furthermore, based on the above definition, some may argue that disordered eating behaviours are a normal part of essential diabetes management due to the necessary monitoring of food content and intake. Therefore, it is important to differentiate between what is considered typical food monitoring and what is classified as disordered eating for this population.

A colloquial term used to describe disordered eating in diabetes is *diabulimia*. This term has developed from the idea of insulin omission being similar to the purging that is found in bulimia nervosa (Broadley et al., 2020). However, there have been some disagreements on using this term due to the feeling that the term is broad and does not capture other restrictive

behaviours (Murphy & Pigott, 2021; Wisting & Snoek, 2020).

Recently, there has been a move towards generating a more inclusive name to describe the difficulties experienced by this group using the acronym T1DE (type 1 disordered eating) (Partridge et al., 2020). It is suggested that individuals with T1DE exhibit the following symptoms: Fear or disturbance regarding one's body weight or shape; direct or indirect restriction of insulin (including purging, laxative use, dietary restriction, or excessive exercise), which are causing harm to health, diabetes distress, or impairments in functioning. Although this is still a working definition, it appears to be the first term used in recognising and conceptualising the difficulties individuals face when living with both conditions. For this study, we will be referring to disordered eating in type 1 diabetes as T1DE and using the above criteria.

The aetiology behind eating disorders and disordered eating is complex, with most research agreeing that it is multifactorial, involving the interactions of biological, sociological, and psychological factors (Collier & Treasure, 2004; Rikani et al., 2013). Several of the risk factors identified across eating disorder research are also associated with day-to-day type 1 diabetes management, which include dietary restraint, monitoring of food intake, weighing food, and striving to achieve blood glucose targets, which may increase perfectionist tendencies (Goebel-Fabbri, 2009; Murphy & Pigott, 2021; Pinhas-Hamiel et al., 2015).

Some people with type 1 diabetes may also experience insulin-related weight gain at the point of diagnosis or following a period of reduced diabetes management. This can lead to body dissatisfaction and a fear of further weight gain, causing some individuals to restrict their insulin intake to achieve a desired weight (Goebel-Fabbri, 2009). Additional difficulties around the relationship with food can develop from the experience of having hypoglycaemic episodes, where the individual would be encouraged to consume sugary food and drink that

may be considered ‘bad’ foods to increase their blood glucose to a safe level quickly. This consumption of ‘bad foods’ may lead to feelings of guilt and result in further restrictions on eating, triggering a cycle similar to individuals with bulimia (Pinhas-Hamiel et al., 2015).

Despite several studies looking at the risk factors involved in developing T1DE, little focus has gone into recovery factors. To date, there is no consensus on how recovery is defined in T1DE. Recovery in typical eating disorders (ED) is primarily based on the measure of symptoms and symptom reduction (Wetzler et al., 2020). It predominately focuses on factors such as weight and behavioural change (i.e. lack of bingeing, purging, and restrictive eating patterns). However, with type 1 diabetes, there is a need to engage in consistent carbohydrate counting and monitoring of food intake that never goes away. Therefore, ‘recovery’ in this group is likely to look substantially different to other EDs.

There has been limited research into recovery from T1DE. This study aims to understand this process further and explore how individuals define the word recovery. Understanding the key components to recovery in T1DE would help inform interventions and help to identify any differences present in people living with type 1 diabetes. These differences need to be identified so that individuals who enter eating disorder services can have the necessary adaptations made to their treatment plan. Furthermore, understanding the recovery factors that individuals with lived experience have identified as essential to their recovery may help to identify factors that may have not previously been considered by professionals. The research may also help to identify recovery factors that could be transferable to individuals with EDs outside of type 1 diabetes.

## **Method**

### ***Participant Recruitment***

Inclusion criteria were participants resident in the UK, eighteen years and older, living with type 1 diabetes who self-identified as being ‘in recovery’ or ‘recovered’ from type 1 disordered eating. Participants did not need a formal diagnosis but were asked if they had ever met the following criteria taken from Broadly et al. (2019): Fear or disturbance regarding one’s body weight or shape; direct or indirect restriction of insulin (including purging, laxative use, dietary restriction, or excessive exercise) which are causing harm to health, diabetes distress, or impairments in functioning. The definitions of ‘recovered’ or ‘in recovery’ were left ambiguous as the study was interested in how people defined these concepts. It was felt that setting criteria for recovery would bias this process.

The study was advertised via a recruitment poster on Twitter, which at the time of study design had high levels of engagement from the type 1 diabetes community. Interested participants were asked to complete an initial survey that asked for basic demographic details, such as age, gender, and duration of diabetes. Informed consent was gained at this time. Participants who met the inclusion criteria were invited for an interview.

### ***Data Collection***

Data were gathered from thirteen transcribed semi-structured interviews (see Appendix D), which were conducted by the first author between November 2022 and January 2023. The interview length varied between 35 minutes to 120 minutes. All interviews took place remotely through Microsoft Teams and were recorded.

Transcription and analysis were undertaken by the first author in line with constructivist grounded theory (Charmaz, 2014). Once transcribed, audio and video data were destroyed to protect confidentiality. In interviews, participants were asked about the word recovery and

what it meant to them, alongside what they believed the factors were that contributed to this process. As the information gathered should be shaped by evolving data (Charmaz, 2014), questions were adapted throughout the process to investigate emerging themes from previous interviews. This process continued until data saturation occurred, that is when interviews were no longer adding new information to form new codes.

### ***Design***

A grounded theory approach was selected due to the limited research and knowledge on the topic area. This approach is helpful for areas that do not have an existing evidence base (Chun Tie et al., 2019). Grounded theory was also selected as the authors were interested in developing a theory of recovery. It was hoped that by utilising a grounded theory approach, new information would come to light and lead to a deeper understanding of recovery for this population.

Constructivist grounded theory differs from traditional grounded theory through its epistemology. The constructivist component is in line with the first author's epistemological stance of constructivism, the idea that knowledge is constructed from our experiences and the meaning we create from them (Fosnot, 2013). It was anticipated that every individual interviewed would have a unique journey, and this study was primarily interested in how individuals make sense of this process and construct their own interpretation of what recovery looks like. Despite utilising a constructivist approach, all the essential criteria of traditional grounded theory, such as simultaneous data collection, coding, memo writing, and data saturation, were still utilised (Charmaz, 2014).

### ***Ethical Considerations***

This study was granted ethical approval by the Bangor University School of Psychology Research Ethics Committee (Ref: 2022-17125; see Appendix A). All participants were

provided with an information sheet about the study, giving them information to decide whether or not to take part. Participants who took part in the interview were reimbursed for their time with a twenty-pound voucher. During the interview, participants were reminded that they could request a break or terminate the interview at any point. Participants were also debriefed at the end of the interview and were offered to be sent a summary of the results once the final paper had been written.

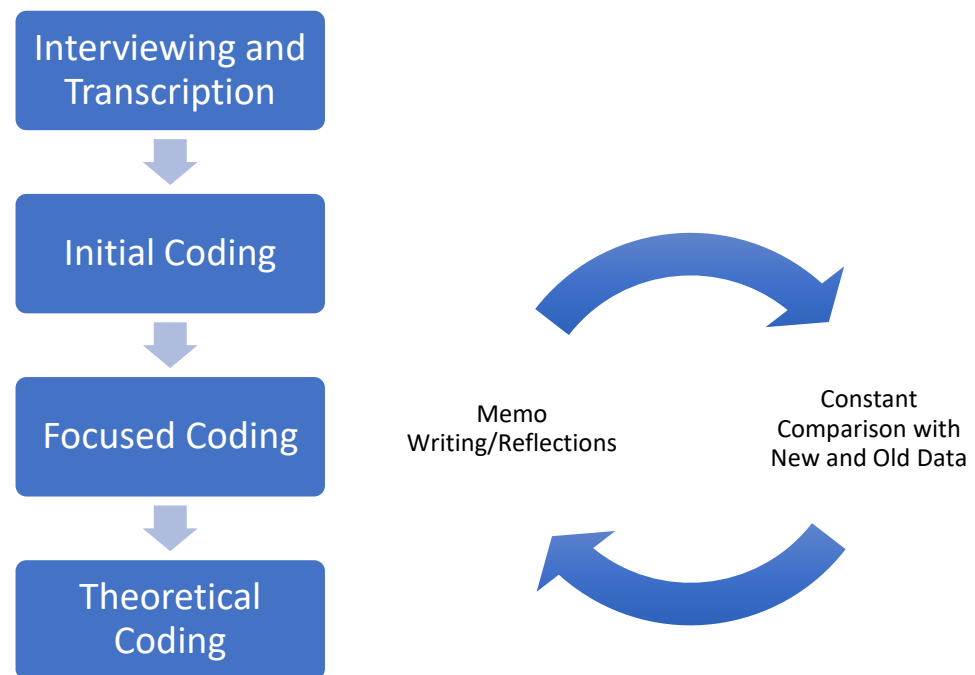
Consent forms, information sheets, and the interview schedule were drafted up and were sent to a patient reference group for feedback. This group consisted of health-care professionals and experts by experience.

### *Analysis*

Interviews were anonymously transcribed, coded, and analysed by the first author. Each interview was transcribed, and each successive analysis then informed future interviews. This is in line with the principles of grounded theory, which state that data collection and analysis should occur side by side (Charmaz, 2014). Transcribed data underwent a three-step process: Initial coding, focused coding, and theoretical coding. Figure 2 provides a summary of the process adopted, which was informed by Charmaz (2014).



**Figure 1.** The Analytic Process



The first phase was initial coding, which involved line-by-line coding and the creation of ‘labels’ to segment the data (Charmaz, 2014). In the second phase, the initial codes were used to form more focused codes. Focused codes were created by identifying codes that were more prevalent and significant in the data. Lastly, these focused codes were grouped into larger theoretical categories, where the researcher linked the categories to the core concept of recovery and made sense of how these categories related to each other. This process continued until theoretical saturation was achieved. It was felt that the last interviews were observing the same concepts and themes as the first few interviews, and therefore, a decision was made to stop at thirteen participants as no new themes were being generated.

Throughout this study, memo-writing took place throughout the analytic process to help catch thoughts, make comparisons, and trigger questions about the subsequent interviews. After each interview, the researcher wrote a memo to reflect on any new information gained as well as compare the new data to existing data (see Appendix E).

### *Quality Assurance*

Constructivist grounded theory proposes that the researcher is a co-participant in the study in that their background will influence the research (Charmaz, 2014). This means that the researcher should practice reflexivity throughout the study. Therefore, this study acknowledges the researcher's position as well as that of the participants and how the interactions between them informed the theory created.

To position the author, I am a white female trainee clinical psychologist in my 30s with no physical health conditions. I had some experience working within a specialist diabetes service and, therefore, had some pre-existing knowledge of the complexities of diabetes and psychology, which could have implications for the identification of certain codes and processes. To promote research quality and integrity, I kept memos reflections and held discussions with the research team, which helped to monitor any biases and assumptions. Despite this, there may be hidden biases present that I was not aware of. It is hoped that following the methodology of grounded theory and its utilisation of constant comparison, as well as consistent questioning of the data, has broadened my immediate assumptions and mitigated potential significant biases.

### **Results**

#### *Participants*

Thirteen participants met the inclusion criteria and took part in a semi-structured interview. Of the thirteen participants, eleven were female, and two were male. All participants were resident in the UK. Ethnicity was not recorded which is acknowledged as a limitation within the discussion section. Participants were aged 28-68 (m=40.69). The average duration of diabetes was 28.77 years. Due to concerns around confidentiality, we have chosen not to list the participants by their age, sex, and duration of diabetes, as this

could lead to individuals being identifiable. However, no visible patterns were observed between reported demographics and recovery duration.

### ***Concept of Recovery***

Before discussing the process of recovery, it is essential to understand how the term recovery will be used. Throughout the interviews, participants varied in the terminology they used to describe this process. Some of the words participants used to describe this process were: “in recovery”, “stable recovery”, “journey”, and “recovered”. Some participants felt that the term recovery was unhelpful as it was not possible to fully recover due to the nature of diabetes:

*“I don’t particularly like the word recovery because I think people can often think you are kind of recovered, but I think it’s like an ongoing thing, and it’s like because kind of food and insulin and blood sugars are all part of my everyday life, it’s not kind of like recovery from a drug addiction where you cannot not engage with that because it’s something you’re kind of faced with every day.”-Participant 13*

A further participant proposed that using the term could mislead people into thinking the problem is no longer a difficulty, stating:

*“I think also recovery can be quite loaded because when you start saying you’re in recovery or even recovered, I think people think that the problem just goes away and that you don’t have it anymore and I think it can be quite misleading, especially you know to like your employers or whatever and even to some healthcare professionals. I think recovery is quite a loaded word and I don’t think it’s always the right word for the space that you’re in.” - Participant 7*

Whilst not all participants felt utilising the term ‘recovery’ was helpful, there was an acknowledgement that a term is needed to define this process in some capacity to instil hope in people that improved quality of life is possible, with one participant stating:

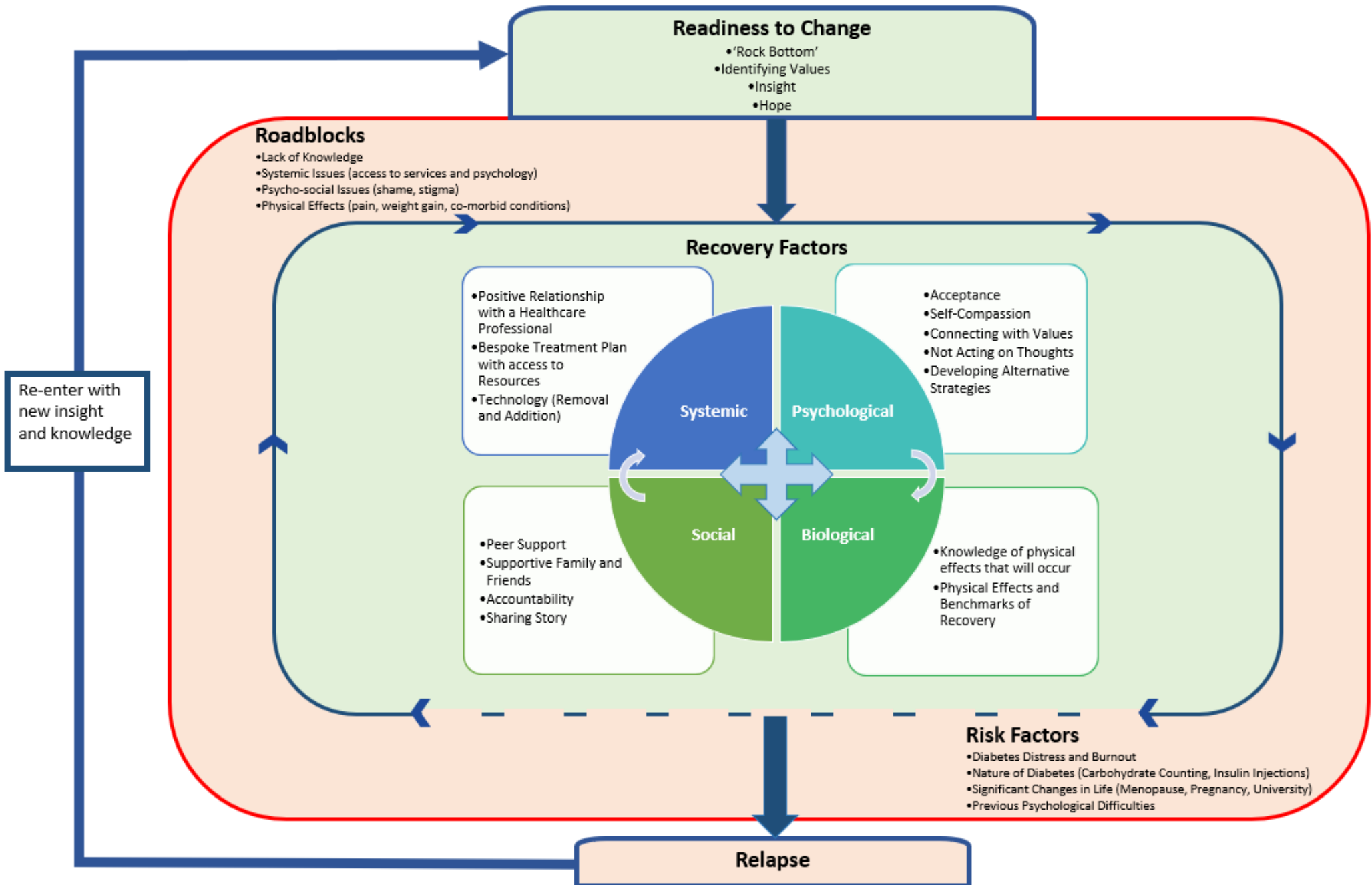
*“I do think recovery is a good term in the wider context as well, so I think it's really important for others who are in the height of where they are on their journey to realize recovery is possible.” -Participant 2*

Based on the current data, this paper will refer to individuals making changes to address their TIDE as being ‘*in recovery*’. It is recognised that there will be limitations and differing preferences for using this terminology, but this word choice resonated the most with the interviewed participants. What was consistent across the data was that recovery within TIDE is a non-linear process that involves periods of relapse and remission. Even after a period of relapse, individuals learned valuable information that would contribute to maintaining their recovery in the future. It was, therefore, important to utilise a term that could incorporate the process of relapse.

### ***The Process of Recovery***

After conducting thirteen interviews, five major categories were constructed and linked to the process of recovery. These are presented as the 5Rs of Recovery: (1) readiness to change, (2) roadblocks, (3) recovery factors, (4) risk factors, and (5) relapse. These five categories were present in all thirteen interviews to varying extents. Underpinning each category was a combination of biological, psychological, social, and systemic factors. The proposed model (see Figure 2) presents these categories. This model illustrates that recovery is a non-linear, multifactorial process that must be looked at holistically to include recovery in both physical and mental health. Each category within the model is presented and explained below.

Figure 2. Proposed Model of Recovery



### ***Readiness to Change***

Participants described that for them to consider themselves ‘in recovery’, they first needed to feel ready to make changes in their lives. Becoming ready to change was different for each participant and seemed dependent upon the level of insight the participant had into their difficulties at the time. In some instances, family members, friends, or other health professionals bringing the issue up sensitively helped to encourage insight into their difficulties. One participant spoke of how they could not recognise what they were doing as problematic.

*“I found it difficult, just because I didn't see the problem I couldn't see the problem. All I saw was, and the best way to look at it, all I saw when I looked in the mirror was a picture of health for me that I was petite.”* -Participant 5

In more extreme instances, participants had to experience a ‘rock bottom’, with some participants explaining that they suffered a significant amount of loss in relation to their family, career, and health before they were able to contemplate change.

*“And so suddenly, like I've lost the one thing that I wanted my entire life. That I've been working for. I had an opportunity to do something totally different”.* -Participant 1

Additional factors that helped encourage a readiness to change included connecting with values and having hope that change was possible.

*“I was happy with what I was doing, like I did not care, and by the end of it, I wanted to make a change, but I don't know what happened to make me think differently. It just sort of all tied together. I guess part of it was looking at my values, like what's important to me. Thinking about my kids in particular with my family and my friends, university like hobbies, I play netball and that was like quite a big incentive to get back to netball because I can't play when my blood sugars are high. And again, going there, exercise is okay, but then it's seeing my friends and having like that company as well. I know that I need to look after myself like, I*

*keep being told, I gotta come first, I gotta look after myself and then I can be a better mum, I can be a better friend, I can be a better \*(career omitted due to identifiable information) and obviously I don't have the energy to do half of that when my blood sugars are really high and I'll end up in hospital again.”-Participant 3*

### **Roadblocks**

Participants reported that once they were ready to change, they were often met with ‘roadblocks’ which sometimes prevented them from entering the recovery cycle. These factors were widely systemic in nature, with participants reporting a lack of specialist services for people with T1DE. Some participants shared how they were told they did not meet the criteria for eating disorder services. One participant described the following:

*“I felt really isolated at first, and one actual healthcare professional said to me, you don't fit in a psychiatric hospital. Your BMI is not low enough to be admitted for an eating disorder and you're well enough to be discharged from acute hospital. We don't know where to put you and it's like, well, okay, fine, but that doesn't leave me with anywhere to go.” -Participant 7*

In addition to this, some participants reported that feelings of shame and stigma stopped them from asking for help. In some instances, when participants came forward, they did not feel believed or felt invalidated, resulting in further stigmatisation and isolation.

*“It was as if the approach from health care professionals had all combined to just invalidate me. I just wasn't worthy of taking up space, quite frankly, but that that's where it got me. It nearly killed me those attitudes and then when you've got to manage this disease alongside that you know....” -Participant 6*

Other roadblocks participants encountered were to do with not having the knowledge on where to start with recovery or a lack of awareness of the physical effects of reintroducing insulin, such as physical pain and weight gain. One participant described their experience as follows:

*“So it's a constant vicious circle all the time so that I used to get caught up in the I don't want things to change because if I do then this is going to change and this is going to happen (gaining weight) and yeah, so I think it's been really stuck on a bit of a broken record, but I'm going to gain weight and therefore this is just showing you that this is what you need.” -*

Participant 12

Some participants shared that their desire to control their weight was not just down to having a desired body image for aesthetic purposes, but more to separate themselves as much as they could from the stigma of having diabetes.

*“I'm sure you're aware that there's a lot of stigma around about diabetes and it's your own fault you're diabetic because you eat too much sweets or you're too fat or you're too this. So I was removing all of these stigmas that were associated with the condition. For me, for me to look as normal as possible so that people wouldn't make assumptions about me.” -Participant*

5

Therefore, it was found that the complexity of diabetes, the way services are run, and stigmatisation from multiple fronts create a multitude of barriers that can make it difficult for individuals to enter the recovery cycle.

### ***Recovery Factors***

Participants reported multiple factors that helped move into recovery as well as maintain it. Participants reported both individual and systemic factors to their recovery. For clarity, these have been separated into the following categories: Psychological, social, biological, and systemic factors.

#### *Psychological Factors*

The psychological concepts and ideas of acceptance, developing self-compassion, connecting with values, not acting on thoughts, and developing alternative strategies were all listed in varying degrees by participants unprompted. Many individuals reported that



accepting their condition, as well as knowing and accepting that they may gain weight, was helpful for them to move forward. However, to reach this point of acceptance, they reported that a re-evaluation of their values, as well as taking a compassionate stance towards themselves, was instrumental in their recovery.

*“So my self-worth comes from what I do, not what I look like, and that was the biggest probably shift in my values.” -Participant 1*

### *Social Factors*

Most participants felt that social factors, specifically peer support, had been a significant factor in helping them maintain their recovery. It was felt that peer support helped to destigmatise the condition, creating a safe space that instilled hope, validated concerns, and offered advice from people with lived experience. Some individuals even shared that telling their stories to others was empowering and helpful in maintaining their recovery.

*“You know it’s that connection. I don’t say it’s gonna, you know, cure the world or cure everyone, but it’s definitely a factor for lots of people and it’s something that healthcare professionals can’t give. You can’t inject it, but you can definitely look to create those moments with people.” -Participant 3*

Additional sources of social support came from individuals’ friends and family, with some individuals reporting that telling others broke up the secrecy that is often prevalent in eating disorders. Whether forms of social support came from others with lived experiences or through family and friends, individuals shared that informing others of their condition and difficulties gave them a sense of accountability.

### *Biological Factors*

Many participants reported that they were not always made aware of the physical changes that would occur when recovering or the risks that may occur when decreasing their

HbA1c such as retinopathy (Jingi et al., 2017), insulin neuritis (Gibbons & Freeman, 2015), or insulin oedema (Hussien et al., 2022). Insulin oedema, when cells fill up with water upon the reintroduction of insulin, may be mistaken for fat gain. Insulin neuritis is when one experiences nerve inflammation and pain due to significant changes in HbA1c. Some participants reported that not knowing about the above conditions impeded their recovery.

It was reported that being equipped with the knowledge surrounding diabetes and what to expect during recovery was an important aspect of the process. Knowing what to expect helped participants not only prepare and manage for upcoming changes but also empowered individuals, took away some fear, and helped take away some of the blame that they typically felt when their blood glucose levels were not as expected. This, in turn, had the power to prevent a vicious cycle that could occur regarding self-blame and guilt, as well as strengthen the individual's confidence. One participant spoke of how helpful it was to sit down with a professional and discuss the relationship between their hormones and their diabetes.

*"I wish I'd known just how much puberty would affect my diabetes and how much now my menstrual cycle affects my ability to manage my diabetes. Where was that discussion when I was a teenager about my hormones and everything else?" -Participant 2*

In addition, participants spoke about the positive physical effects of recovery. They shared that injecting their insulin as prescribed led them to have more energy to do the things that they previously felt too tired to engage with.

#### *Systemic Factors*

Lastly, systemic factors were mentioned by all participants in the interview. Many participants felt strongly that the system structure let them down at some point, reporting that the structure of the clinic and focus on numbers was unhelpful, with many going away feeling that they were not seen as a person. However, in most cases, participants shared that

although they experienced difficult experiences, at some point, there was typically one professional who made a positive difference in their lives. When asked about the qualities of this person, many participants highlighted the importance of having a person who was non-judgmental and validating and saw them as a person outside of their diabetes.

*“There's a diabetes nurse that started like, just as I needed it.... she's not like fully trained in like the therapies, but she still wants to help and understands it's not as easy as saying take more insulin. She's, like, taking the time to get to know me as well, so she kind of understands why it started. It just feels like I'm actually being listened to.” -Participant 3*

Other systemic factors regarded how language was used and treatment plans were designed. Many participants felt that when they were asked open questions about their diabetes and when language that implied blame was eliminated, they were more likely to engage with their diabetes team. A couple of participants commented about the unhelpfulness of the word ‘control’, noting that since control was a function of their eating disorder, being told they ‘did not have good control’ was triggering. Other participants spoke about how the nature of managing diabetes encourages perfectionism, which the system reinforces.

*“You kind of want a flat line. Not that anyone lives with a flat line, even if they've got a pancreas that works, but you know, that pressure on you, I've got to get it down by another point by next time. And yeah, it's it's a whole lot of pressure.” -Participant 8*

Ultimately, individuals found it helpful when a treatment plan was tailored to their needs, was multidisciplinary and when there was adequate pacing alongside positive reinforcement when an achievement was made.

*“So um it's not just the eating disorder psychiatrist or your diabetes consultant and diabetes nurses, you've got the umm diabetes psychologist and the eating disorder clinician, and then eventually there's been some outreach occupational therapists support which I found has been really, really really helpful because I think you need to work on the practical side of*

*things when you're trying to manage insulin administration so um having regular meals and building up the confidence to have regular insulin doses.” -Participant 12*

One participant spoke of the difficulties they faced when progress was not reinforced:

*“...and the little um sort of wins that I would have for example, like I didn't wear a sensor for 2 1/2 years and the fact that I put my sensor back on was a massive thing for me, but they didn't see that. So it was like they had bigger expectations, and you feel like you have to prove yourself every time.” -Participant 7*

A bespoke treatment plan appears important when considering the use of technology.

Whilst many participants reported that the use of diabetes technology helped them with their disordered eating, there were a few participants who spoke of how technology hindered their recovery. This area requires further research, but the link between recovery and technology seemed to depend on the function of the eating disorder and whether technology was used pre-eating disorder or acquired whilst experiencing the eating disorder.

Some participants shared how the technology allowed them to better manage their diabetes by taking away the trigger of injecting insulin and/or making it easier to monitor their diabetes. However, other participants reported that technology such as pumps took away further control, which they felt generated more distress. In some cases, individuals reported that the constant notifications and awareness of their blood glucose levels from their continuous glucose monitor (CGM) led to feelings of being overwhelmed and sometimes led to diabetes burnout.

*“So I was using technology a lot more, but it was quite intense, and I was having to do a lot and think a lot and had someone trying to help me, which was great, but um, it was just it wasn't, it probably took up a bit too much time and energy and I think that's where I started to step away a lot more and be like I can't do this and I think that's where burnout*

*occurred....Umm so I think in that sense it's definitely it's been really helpful, but I think there is a technology burnout as well that sometimes it's just too much information” -Participant 12*

### **Risk Factors**

It became apparent that the risk factors individuals with T1DE experience are constant and dynamic, hence the decision to put these alongside recovery factors within the model in figure 2. It is proposed that the various recovery factors help an individual work through the risk factors they may be faced with and prevent relapse. However, a combination of these risk factors and/or a lack of recovery factors has the potential to overwhelm the maintenance cycle and lead to relapse. Risk factors were broken down into the following categories: Significant changes in life (i.e. menopause, pregnancy, identity struggles, university), experiencing diabetes distress or burnout, the nature of diabetes (i.e. insulin injections, carb counting), and previous psychological difficulties.

Participants reported that when there were big changes in their lives, they noticed that their difficulties with their eating increased. Similarly, when participants were experiencing heightened distress related to their diabetes or feeling burned out, they were more likely to engage in disordered eating behaviours. It could be proposed that this is related to the idea of control that is sometimes linked to typical eating disorders. One participant described this as follows:

*“I think that's had an impact on the way I think about things, but yeah I started manipulating my insulin to give me freedom with food, and then I realised actually, I just disengaged completely. I didn't omit my insulin to lose weight purposely. That was like a secondary thing that happened. It was more for me about having that control or just, I can't get to grips for my diabetes. I can't do it, so I'm just going to be super, super rebellious and just control not managing my condition then.”-Participant 2*

Another participant described:

*“And so yeah, um control was a massive thing. And also like I think it depends on where you are in your life as well. Like work was really bad and stressful and you know, my personal life wasn't great and lots of other things were going on. So I kind of used the disordered eating as a way of controlling how I felt and what was going on in the wider part of my life”-*

Participant 7

A couple of participants reported that they felt the difficulty they experienced with others accepting their identity with the LGBTQIA+ community further increased their difficulties with their diabetes. One participant felt that individuals within this community may be at more risk:

*“I speak to other lots of people with diabetes now and I just asked the question I said, you know, you were dealing with your sexuality, did you feel you took that out on your diabetes quite a lot and the answer I normally get um yeah I actually did. I'm trying to make a link between that as well, so whether that's relevant or not, I don't know. But it was, it was just, you know of significant importance to me. I feel we should be looking at whether young people who are you know, under the LGBT community, are they potentially a vulnerable group that we should be giving a bit more support to?” -Participant 2*

Another rationale for why significant changes in life may increase disordered eating behaviours involves biological factors such as hormonal changes. This means that significant moments during puberty, pregnancy, and menopause may make diabetes hard to manage but also may bring about triggers that increase the likelihood of engaging in disordered eating behaviours. One participant spoke of the link between hormonal changes and the importance of being aware of triggers relating to these changes.

*“I know a lot of people mention menopause is really hard time to manage your condition. So again, hormonal changes. How much does that impact how I feel about my body? I think every woman has a day where they just feel ugh. You know I can't describe it any better than that, but sorry, but you know you have those days and you, you don't even feel like you don't*

*even feel big, you just feel a bit shapeless, which is almost worse. I don't know if every woman has these, but you know, they probably lead into your hormones and they, so I do wonder how much hormonal stuff has an impact on my triggers that I'm not actually aware of.” -*

Participant 2

### **Relapse**

Participants highlighted that relapse is a part of the recovery process. As one individual highlighted:

*“I think you're kind of at each point, you're learning something. So whilst you're kind of maybe having a little bit of a relapse, actually the journey that I'm having is different now, and they're kind of, they're shorter and they don't last as long or you know I can manage to turn things around quite quickly. Whereas I guess previously that wasn't the case. So, I think, yeah, I've kind of managing a bit different.” -Participant 12*

Based on the experiences of the study participants, it is suggested that relapse should be viewed as a period of growth and change. It is important to support individuals during this time by encouraging them to reflect on their experiences of relapse, including the triggers that led to it. In addition to this, reminding individuals of their initial motivation to change can help them re-enter the maintenance cycle. The participants emphasised that reflecting on the recovery process and being aware of the cycle was crucial in moving forward.

*“So yeah, it's an interesting one because I am very well aware that I need to get to know myself to understand my triggers, to know how to not dip back in at any point and without access to people who have studied what recovery and relapse can look like you're kind of in the dark.” -Participant 2*

This highlights the need for not only further research but also for psychological formulations to help support individuals in maintaining recovery.

## **Discussion**

This study explored the recovery process in people living with Type 1 disordered eating. A theory of recovery was developed by data grounded in the narratives of people with lived experience. Whilst each participant's journey was unique, involving a combination of different recovery factors, there were similarities in the overall process.

Based on these consistencies, this study proposes a theory that recovery within T1DE is a non-linear, multifactorial process that must be looked at holistically to include recovery in both physical and mental health. This proposed recovery model is, therefore, able to acknowledge recovery related to clinical outcomes (i.e., improved glycaemic outcomes, reduction in insulin omissions) whilst also attending to an individual's general well-being (i.e. connecting with values, social connectedness, and self-compassion). This allows for a more person-centred approach to recovery, which can be tailored to the individual and puts emphasis on improving their overall quality of life. This differs from typical eating disorder recovery frameworks where the focus is typically on symptom reduction (i.e., weight restoration or reduction of purging).

The complexity of living with T1DE means that there is no prescribed list of recovery factors that an individual must have or achieve. However, this study proposes that when an individual has a combination of recovery factors stemming from the system and social network around them, as well as when they are equipped with the knowledge to support their physical and mental health, they can maintain a period of recovery. The more resources available to pull on, the more likely they are to maintain this period long-term.

Due to the nature of T1DE and general life circumstances, risk factors will always have the potential to overwhelm this cycle. Should the individual have enough resources and knowledge at the time to pull from, they are able to continue their period of recovery. However, in some instances, the risk factors may overwhelm the cycle and lead to a period of relapse. It



is proposed that even at this moment, the individual is still learning from their experience, and when re-entering the cycle, they will be equipped with new insight and knowledge that will help them move forward.

The findings of this study need to be considered in the context of the study's limitations. The recruitment for this study took place on social media, specifically Twitter and was shared by advocates for T1DE. It is possible that this recruitment process limited the variety of participants to individuals who typically use this platform (i.e., other advocates, academics, and healthcare professionals). As online recruitment considers a level of digital literacy and access to technology, this way of recruiting may have led to bias in the age of participants or to possibly a bias against people of lower socio-economic status who may not have access to the technology required (Oliveri et al., 2021).

In addition to this, we recognise that not recording the ethnicity or the socioeconomic status of the participants are further limitations to the study's generalizability across populations. We recognise that our participants would fall under the WEIRD (western, educated, industrialized, rich, and democratic) population category (Henrich et al., 2010) which are more commonly heard from in research and so we cannot generalise how recovery may look outside of this group. Research on social inequality in diabetes (Bernard-Kelly & Cheryñavvsky, 2020) has highlighted that socio-economic inequalities present a risk to the management of diabetes and so it is likely that there may be additional factors to the recovery of T1DE that our study is missing. For the above reasons, it is recommended that this model be reviewed with individuals from more diverse and marginalised communities to further understand its generalizability to other populations.

When recruiting for this study, a definition for 'recovery' in T1DE was not provided to individuals during the recruitment process. Whilst we consider this a strength and necessity of

the study in order to gain an objective viewpoint of how individuals define their journey, we must acknowledge there may also be a limitation alongside these benefits. It is possible that some individuals may have felt they were not ‘recovered’ enough to participate and, therefore, did not apply to take part in the study.

In addition to this, the minimum age to participate in the study was 18, with no maximum age. We consider the broad age range of participants a strength of this study as it was able to provide viewpoints from across the age range. However, we were unable to look specifically at any differences in recovery between age groups. It could be proposed that recovery from TIDE may look different depending on age. Some of these reasons may be due to differences in how TIDE has been perceived over the years, changes in services, social media, and new developments in technology. Many of the participants spoke about how TIDE was not a ‘concept’ when they were initially experiencing it, which will have played a role in their journey to date. It would be interesting for further research to examine if there are differences in recovery between age groups.

Lastly, it was noticed that within this study, there were differences in how participants perceived the helpfulness of technology for recovery. Some individuals felt strongly that technology saved their lives, whilst others felt that the use of technology fuelled their perfectionism and, in some instances, led to technological burnout. Further understanding of how this plays a role for individuals is important for further technological advancement as well as clinical practice.

Despite the limitations, this study has highlighted that some individuals living with TIDE do feel that a process of ‘recovery’ is possible and that one can improve their quality of life despite struggling with this condition. It is hoped that this can instil hope and encourage

change in individuals living with T1DE as well as help professionals. This study proposes several implications for clinical practice.

From a systemic perspective, this study has highlighted the importance of a multidisciplinary diabetes team that is nonjudgmental and knowledgeable in T1DE. Participants highlighted that they were more likely to come forward with their difficulties and work with their team when they felt the team was supportive. Furthermore, when people living with T1DE come forward, it is important that they feel believed, listened to, and have access to resources that can help them.

Individual accounts of psychological concepts such as self-compassion, acceptance, emotion regulation, and living in line with values linked into different therapeutic approaches, notably techniques found within third-wave therapies such as Acceptance and Commitment Therapy (ACT). Evidence has been increasing for the use of ACT with eating disorders (Manlick et al., 2013; Onnink et al., 2022). Results from this study also appear to be in line with current research into a specific intervention for T1DE, specifically the “The comPASSION Project”, which lists these as key components in their psychological interventions that have been shown effective for T1DE (Partridge et al., 2020).

Lastly, psychological formulation can be a helpful tool that helps build an overall picture or map of a client's experiences and current difficulties (Johnstone, 2018). Formulating can help both teams and individuals understand presenting problems in more detail and be used to help inform treatment. It is hoped that the presented model and theory of recovery can aid in the formulation process to help diabetes teams, as well as the individuals living with T1DE, have a better understanding of the difficulties faced. It is also hoped that this model can be helpful in assisting individuals to identify their strengths and factors that may be useful to their

recovery, as well as being aware of the potential risk factors they may face so that they are better protected from these in the future.

In conclusion, this study offers a theory of recovery based on the experience of thirteen individuals with type 1 disordered eating. Our findings have also been able to suggest some common recovery factors and barriers to recovery. Those working with this population may want to consider how their services can facilitate any of the listed recovery factors as well as limit the barriers mentioned.

### **Funding**

None. This research was undertaken as part of a doctoral research project.

### **Conflicts of Interest**

No potential conflict of interest to declare.

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## Appendix A: Confirmation of Ethical Approval by Bangor University School of Psychology

**From:** ethics@bangor.ac.uk <ethics@bangor.ac.uk>  
**Sent:** 22 June 2022 11:34  
**To:** Ronda Bell <rnrm20xky@bangor.ac.uk>  
**Subject:** Ethical approval granted for 2022-17125 Turning the T1DE: Recovery Factors in Type 1 Disordered Eating

Dear Ronda,

2022-17125 Turning the T1DE: Recovery Factors in Type 1 Disordered Eating

Your research proposal number 2022-17125 has been reviewed by the [Pre-Aug 2021] School of Psychology Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.



## **Appendix B: Research Protocol Submitted to Ethics**

### **1. Project title**

Turning the TIDE: Recovery Factors in Type 1 Disordered Eating.

### **2. Supervision**

The Principal Investigator is Ronda Embick, a Trainee Clinical Psychologist at the North Wales Clinical Psychology Programme at Bangor University. The proposed study comprises partial fulfilment of the requirements of a Doctorate in Clinical Psychology (DClinPsy). Dr Rose Stewart will be the primary research supervisor and will provide supervision for all aspects of the project. She will act as Chief Investigator. Additional supervision and support around research methodology will be provided by the academic supervisor, Dr Mike Jackson.

### **3. Background**

Type 1 diabetes is a lifelong condition in which the pancreas produces little to no insulin, the hormone needed to allow glucose to enter cells and produce energy (Goodhart et al., 2017). Individuals living with type 1 diabetes are required to self-manage the condition which involves significant changes to an individual's lifestyle involving daily carbohydrate counting, monitoring of blood glucose levels throughout the day, and daily insulin injections (Goodhart et al., 2017). For many, the burden of living with diabetes can lead to psychological distress and research has shown that those who live with type 1 diabetes have an increased risk of developing psychological issues and in particular eating disorders and disordered eating when compared with individuals without diabetes (Hanlan, et al., 2013).

Differing definitions exist behind the terms eating disorders and disordered eating. The term eating disorders tends to refer to the psychiatric labels presented in the Diagnostic and Statistical Manual of Mental Disorders (5th Ed; DSM-5; American Psychiatric Association, 2013) which can include difficulties involving extreme food restriction (anorexia nervosa) to difficulties with overeating and unhelpful compensatory behaviours (bulimia nervosa and binge eating disorder). These diagnostic labels, however, struggle to capture the difficulties specific to those living with type 1 diabetes, where disordered eating presentation may look significantly different due to the unique role of insulin. Without a regular and adequate dose of insulin, a person with diabetes can induce a state of hyperglycaemia (high blood glucose) and ketosis, where the body breaks down fat cells in order to gain energy, thereby causing weight loss. Where people with diabetes become aware of this, they may begin to deliberately underdose or entirely omit their insulin in order to lose weight. This behaviour poses significant risks, both in the form of long-term health complications caused by chronic high blood glucose levels and significant acute risks in the form of diabetic ketoacidosis; a serious and often life-threatening 'chemical meltdown' within the body. Further diabetes specific disordered eating behaviours may occur when a person with diabetes is in a state of hypoglycaemia (low blood glucose), as they are biologically driven to eat significant amounts in order to rebalance their blood glucose levels, often resulting in dysregulated binge eating behaviours.

Both the DSM-5 and ICD-10 classifications for eating disorders do not include diabetes specific elements such as diabetic ketoacidosis, hyperglycaemia, and hypoglycaemia within the diagnostic criteria (Broadley et al., 2019). Therefore, individuals with type 1 diabetes who deliberately restrict their insulin for the purposes of weight loss may be experiencing high risk life threatening complications as a direct result of their behaviour, but still not fulfil diagnostic

criteria for eating disorder diagnoses and may therefore be unable to access support and treatment from traditional eating disorder services.

The term disordered eating typically refers to symptoms that are not severe or frequent enough to be considered a diagnosable eating disorder and includes all behaviours related to weight loss (Pereria et al., 2007). It could therefore be argued that people with type 1 diabetes who manipulate their insulin for the purposes of weight loss would fall under this category. However, given the aforementioned high risk of life threatening complications as a direct result of this behaviour, disordered eating is considered by many as a term that is not 'severe' enough. Despite this, there are varying viewpoints on whether having a specific eating disorder diagnostic label for people living with diabetes and disordered eating could cause more harm than good (Murphy & Pigott, 2021). One colloquial term that is associated with disordered eating in diabetes is diabulimia which is a term that has developed from the idea of insulin omission being similar to purging that is found in bulimia nervosa (Wisting & Snoek, 2020). However, there have been some disagreements on using this term with some feeling that the broadness of the term does not capture other restrictive behaviours that may be occurring in type 1 disordered eating (Wisting & Snoek, 2020)).

Ultimately, there is still no consensus on the definition of what disordered eating is in type 1 diabetes (Broadley et al., 2019) or what it should be referred to as (Patridge et al., 2020). Recently, there has been some move towards generating a name to describe the difficulties experienced by this group using the acronym T1DE (type 1 diabetes and disordered eating) (Broadley et al., 2019). Their definition of T1DE is a person living with type 1 diabetes who presents with the following: Fear or disturbance regarding one's body weight or shape; direct or indirect restriction of insulin (including purging, laxative use, dietary restriction, or excessive exercise) which are causing harm to health, diabetes distress, or impairments in functioning. Although this is still a working definition as their research continues, it appears to

be the first term used in recognising and conceptualising the difficulties individuals face when living with both conditions. For the purpose of this project and recruiting participants, we will be following these criteria.

The aetiology behind eating disorders and disordered eating is complex, with the majority of research agreeing that it is multifactorial, involving the interactions of biological, sociological, and psychological factors (Collier and Treasure, 2004; Rikani et al., 2013; Solma, 2021). Several of the risk factors that have been identified across eating disorder research are also associated with day-to-day type 1 diabetes treatment, which include dietary restraint, monitoring of food intake, weighing food, and striving to achieve blood glucose targets which may increase perfectionist tendencies (Goebel-Fabbri, 2009; Pinhas et al., 2015; Murphy & Pigott, 2021). Some individuals may also experience insulin related weight gain at the point of diagnosis or following a period of reduced diabetes management, which may contribute to body dissatisfaction. This fear of further weight gain can lead to insulin restriction in an effort to achieve a desired weight (Goebel-Fabbri, 2009). Further difficulties around the relationship with food can also develop from the experience of having hypoglycaemic episodes where the individual would be encouraged to consume sweet food and drink that may be considered 'bad' foods in order to quickly increase their blood glucose to a safe level. This may lead to feelings of guilt and result in further restrictions in eating causing a cycle similar to individuals with bulimia (Pinhas et al., 2015).

Despite several studies looking at the risk factors involved in developing T1DE, little focus has gone into looking at the factors that may be involved in recovering from T1DE. To date there is no consensus on how recovery is defined in T1DE. The consensus of what recovery looks like in eating disorders (ED) is largely based on the measure of symptoms (clinical symptom ED recovery framework) (Wetzler et al., 2020). It predominately focuses on factors such as weight status and behavioural change (i.e. lack of bingeing, purging, and restrictive eating

patterns). However, within type 1 diabetes there is a need to engage in consistent carbohydrate counting and monitoring of food intake that never goes away. Therefore ‘recovery’ in this group is likely to look substantially different to other EDs.

Understanding the key components to recovery in T1DE would help inform treatment interventions and also help to identify differences that may be present in people living with type 1 diabetes. These differences are important to recognise for individuals who may enter eating disorder services and need adaptations made to their treatment plan, goals and progress measures. Furthermore, understanding the recovery factors that individuals with lived experience have identified as important to their recovery may help to identify factors that may have not previously been considered. The research may also help to identify recovery factors that could be transferable to individuals with EDs outside of type 1 diabetes as there is currently a move towards adopting a personal recovery framework for EDs (Wetzler et al., 2020). This framework is particularly interested in a more holistic approach to measuring recovery (i.e. the social, psychological, emotional, behavioural, and physical factors) as opposed to focusing purely on measuring changes in symptoms. However, this is still a relatively new concept and limited research on personal recovery for EDs exists (Wetzler et al., 2020).

At the time of writing this, there has not been any research into a personal recovery framework for T1DE. Only one study could be found that tried to make sense of the process of recovery in T1DE (Harison et al., 2021). However, this was model specific (CBT) and as a result may have some limitations in explaining the journey of recovery.

#### **4. Research question**

It is hoped to interview people who define themselves as ‘recovered’, ‘recovering’ or ‘in recovery’ from T1DE to better understand what recovery means to them and answer the following questions:

1. What are the experiences of recovery for individuals with T1DE?
2. What are the common factors or themes that helped individuals recover from T1DE?
3. What does ‘recovery’ mean to individuals with T1DE?

It is hoped that this will achieve three main objectives:

1. Understand the process and experience of recovering from T1DE.
2. Identify specific factors and themes that have helped them move to recovery.
3. Move towards defining recovery in T1DE.

It is hoped that looking at the journey of recovery with individuals with lived experience will help to shape a clearer definition and understanding of what recovery looks like in T1DE which can inform future interventions.

The terms ‘recovered’, ‘recovering’ and ‘in recovery’ will be used when recruiting participants. It is hypothesised that recovery would not be a static linear process and that there will be a variety of opinions on what recovery means to a particular individual as well as different recovery factors involved. It could perhaps be that individuals feel they are always ‘in recovery’ similar to how the term is used in substance misuse whereas others may choose to use the word

‘recovered’. It is also proposed that the process of recovery is not static and so it would be useful to gain perspective from people across the ‘recovery spectrum’ to understand concepts such as relapse. Therefore to have a better understanding of what recovery looks like and how individuals with service users define this process both terms will be used. However, there will hopefully be common themes that show up across participants.

## **5. Method**

### **5a. Participants and recruitment**

- Participants will be recruited from social media platforms. It is hoped that using a variety of platforms will increase the accessibility of the study and hopefully recruit participants from different backgrounds. For this study, new dedicated accounts will be created on these platforms.
- If individuals are interested in taking part in the study they will be invited to complete an initial survey to ensure they meet the requirements for the study. On the survey form, participants will be presented with a consent form, detailing information about the study and informing them of what data will be gathered. They will then be invited to fill out a survey to consent and ensure they meet the inclusion criteria.
- Inclusion criteria will be individuals who are 18 years and older living with type 1 diabetes and are resident in the UK. All participants will be people who consider themselves either ‘recovered’ or ‘in recovery’ from T1DE.
- Participants who meet inclusion criteria will then be invited to take part in a semi-structured online interview to understand their experience of recovery.

- It is anticipated that these interviews will take place over Teams and will be recorded. Interviews will last roughly 1-2 hours and be completed in one sitting. The researcher recognises that this may be a lengthy time for someone to sit and speak about their experiences and so the researcher will ensure breaks are offered throughout and consent is regularly monitored. The researcher will ensure they are in a quiet and confidential space when conducting the interview. Likewise, the researcher will ensure the participant is also in a confidential space and feels comfortable disclosing their experiences.
- The researcher will ensure there is time at the end of the interview to allow the participant to be debriefed and signposted to relevant resources.
- All interviews will then be transcribed and then analysed using grounded theory principles.
- In terms of number of participants, theoretical sampling will be used. This is a process used in grounded theory that involves continuing to collect data until theoretical saturation occurs, a term referring to when no new themes or patterns are emerging from the data (Conlon et al., 2020). However, given the limited timescale for the project, it may not be feasible to obtain full saturation. Pragmatically, the study will aim for a minimum of 6-10 participants.

## **5b. Measures**

- Participants will initially be asked to complete the DEPS-R (Please see appendix). This is a brief screening tool for disordered eating in type 1 diabetes (Markowitz et al., 2010).



- Basic demographic information will be collected for participants including: age, gender, age of diagnosis of type 1 diabetes, diabetes management information (e.g. via injection or insulin pump, use of flash or continuous blood monitoring devices), length of time they have struggled with T1DE, and how long they have defined themselves as ‘in recovery’ or ‘recovered’.
- This study will utilise semi-structured interviews. Collected data will be in the form of audio-files of interviews with participants. These will then be transcribed and stored as word documents on a secure encrypted device.

### **5c. Design and Procedures**

- Participants will be offered a consent form, detailing information about the study and informing them of what data will be gathered. They will then be invited to fill out a survey to consent and ensure they meet the inclusion criteria.
- Participants who meet inclusion criteria will then be invited to take part in a semi-structured online interview to understand their experience of recovery.
- It is anticipated that these interviews will take place over Microsoft Teams and will be recorded. Interviews will last roughly 1-2 hours and be completed in one sitting. The researcher recognises that this may be a lengthy time for someone to sit and speak about their experiences and so the researcher will ensure breaks are offered throughout and consent is regularly monitored. The researcher will ensure they are in a quiet and confidential space when conducting the interview. Likewise, the researcher will ensure the participant is also in a confidential space and feels comfortable disclosing their experiences.

- The researcher will ensure there is time at the end of the interview to allow the participant to be debriefed and signposted to relevant resources.
- All interviews will then be transcribed and then analysed using grounded theory principles.

## **6. Data management and storage**

- The researchers will comply with both NWCPP and BCUHB confidentiality and data protection policies at the time. Interviews will be recorded on Teams and stored on a password-protected BCUHB device provided by NWCPP. Interviews will later be transcribed by the main researcher. All participant names and other identifying information will remain anonymised when presenting the data. All written data will be stored at the Gladstone Centre, Wrexham Maelor and will be destroyed after five years.
- It is anticipated that the study will utilise a grounded theory approach. Grounded theory is a qualitative research methodology that explores and tries to understand processes or patterns that emerge from qualitative data (Glaser & Strauss, 1968). Given that there has been limited research on recovery in TIDE, it was felt that Grounded theory would be a useful tool to help explore this subject area and provide a deeper understanding into the process of recovery.
- Grounded theory (GT) has different methodological genres such as traditional GT and constructivist GT (CGT) (Chun Tie et al., 2019). CGT takes the standpoint that the sharing of experiences between researchers alongside participants leads to the construction of theories about what is happening as opposed to the theories being 'discovered'. A constructivist approach looks at not only what meaning participants make of something, but at how that meaning is created and influenced by wider societal factors such as situations, community, relationships, power, and communication

(Charmaz, 2014). These differences in experience will ultimately have a role in how this experience is viewed. This research will follow a constructivist view and as a result the researcher will be reflecting on their own experiences and become aware of what biases and presumptions may be brought up when interviewing and analysing the data.

- All data collected will follow Bangor University data protection policies, confidentiality policies, and data protection policies.
- All data will be anonymised, recorded and stored securely on a BCUHB device. Participants will be allocated identification numbers in order to anonymise their stored data.
- Any written information will be stored in a locked filing cabinet stored at the Gladstone Centre, Wrexham Maelor Hospital for up to five years, where it will be available should this information be requested post-publication. After this time, all data will be destroyed.

## **7. Feedback**

- Participants will be asked if they would like to receive a summary of the main findings of the project and be sent through an accessible letter at the end of the study.

## **8. Risk Assessment**

- Risks to Researcher: The researcher may have to hear distressing information. Supervision will be an important part of this project to manage any risk to the research.

- **Participant Risk:** Participants may also experience some upsetting emotions when talking through their stories although it is hoped that sharing their stories of recovery may be helpful for some participants. All participants will be made aware of this risk prior to taking part in the research. Should the participant experience distress, the researcher will provide space for this to be explored together. Participants will be informed that they can discontinue from the study at any time and have their data removed. Additionally, the researcher will offer numbers for support after they have completed both the initial survey and again if invited for the interview.

## Appendix C: Participant Forms



RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU  
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME



### Participant Information Form

**Study Title:** Turning the T1DE: Recovery Factors in Type 1 Disordered Eating

**Research Team:** Principal Investigator: Ronda Bell  
Chief Investigator: Dr Rose Stewart  
Academic Supervisor: Dr Mike Jackson

- We would like to invite you to take part in a research study to help us learn more about the experience of recovering from type 1 disordered eating (T1DE).
- Your participation is voluntary.
- This information sheet explains more about the study. Please read in full before deciding if you would like to take part.
- If you are happy to continue and be part of the study please complete this online form [Link]

This project has been reviewed and approved by ~~xxxx~~.

#### What is the purpose of the study?

- This study aims to explore the lived experience of individuals who either are in recovery or who have recovered from type 1 disordered eating (T1DE).
- We are hoping that interviewing people with lived experience will help us identify common factors and themes that shaped their journey to recovery.
- It is hoped that understanding these journeys will help us develop a clearer definition and understanding of what recovery looks like in T1DE to inform future interventions.

#### Who is doing this research?

If you require further information or have questions please contact Ronda Bell at [rmm20xky@bangor.ac.uk](mailto:rmm20xky@bangor.ac.uk)

Version 1. 04/2022.

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RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU  
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME



- The research is being carried out by Ronda Bell, a trainee clinical psychologist on the North Wales Clinical Psychology Programme. Ronda is doing this research study as part of her training.
- The research is being supervised by Dr Rose Stewart, Consultant Clinical Psychologist for the Diabetes Psychology Service in North Wales and Dr Mike Jackson, Clinical Psychologist and Research Director at the North Wales Clinical Psychology Programme.

#### Who can participate?

- Individuals who are 18 or older and are resident in the UK.
- Individuals who may describe themselves as 'recovered' or 'in recovery' from type 1 disordered eating (T1DE).
- You do not need a formal diagnosis, but it may help to understand the definition of T1DE (Allworth et al., 2021) which is people who fit the following 3 criteria:
  - 1. Disturbance in the way in which one's body weight or shape is experienced or intense fear of gaining weight or of becoming overweight. Extreme worrying about your weight or shape, or feeling really scared of gaining weight or becoming [overweight](#)
  - 2. Reducing or skipping your insulin doses [in order to](#) prevent weight gain, severely restricting your food intake, making yourself vomit, taking laxatives and/or exercising excessively in order to lose weight or prevent weight gain.
  - 3. The behaviours listed in above have caused harm to health, have had a big negative impact on your relationship with diabetes, and/or have gotten in the way of you being able to live your life.

#### Do I have to take part?

- **No.** Taking part in this study is completely voluntary. We ask that you read this information sheet carefully before you decide. Please contact Ronda [Bell](#)

If you require further information or have [questions](#) please contact Ronda Bell at [mm20xky@bangor.ac.uk](mailto:mm20xky@bangor.ac.uk)

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[rmm20xky@bangor.ac.uk](mailto:rmm20xky@bangor.ac.uk) if you would like more information or if there is anything you are unsure of.

**What will happen if I take part?**

- You will be asked to provide some basic personal details and some clinical information about your [diabetes](#)
- You will be asked to complete a short questionnaire called the DEPS-R to help us understand your current relationship with eating and your diabetes.
- If you meet the criteria we are looking for, you will be contacted to take part in an interview with Ronda Bell, Trainee Clinical Psychologist.
- Your participation is [voluntary](#)
- You can end the interview at any time.
- You will receive a £20 Amazon voucher as a thank you for your participation.

**How long will the interview take?**

- The interview will take approximately 1-2 hours and is completed in one sitting. Short breaks will be offered during the interview, but you can request one at any time.

**Where will the interview be?**

- The interview will take place online via Microsoft Teams. The researcher will ensure they are in a space that is confidential and quiet.
- We ask that you are also in a quiet and confidential place where you feel comfortable and able to speak safely.

**Are there any possible benefits to taking part?**

- You would be helping us understand more about the experience of recovering from T1DE. The experiences gathered, will inform current research in this area which could be potentially useful in informing definitions of recovery and treatment interventions.
- You will receive a £20 Amazon voucher as a thank you [for taking](#) part after the interview has taken place

**Are there any possible downsides to taking part?**

If you require further information or have [questions](#) please contact Ronda Bell at [rmm20xky@bangor.ac.uk](mailto:rmm20xky@bangor.ac.uk)

Version 1. 04/2022.



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- We are hoping that talking about your recovery will be rewarding and hopeful. However, the journey of recovery may touch on areas of your life that you found distressing.
- You do not have to talk about anything that makes you feel uncomfortable. If at any time during the interview you feel distressed please alert the interviewer to this as soon as possible so that support can be offered.
- If we have concerns about your wellbeing, we may advise you to contact your GP, diabetes teams, or provide you with further numbers for support.

**Will my information be kept confidential?**

- **Yes.** All information about you will be kept strictly confidential. You will be assigned a random number at the start of the research and information about you can only be identified by this specific number, which will only be known to the interviewers. Your research data (i.e. your interview and transcript) will not be connected to your personal details (i.e. name, contact details, etc.).
- If at any time during the study, you disclose any incidents that put yourself or others at serious risk of harm, the research has a legal requirement to breach confidentiality. This means that the researcher cannot keep this information confidential and will be required to report the information to the relevant person or authority responsible. Wherever possible, the researcher will inform you of when they will need to breach confidentiality. However, the researcher can share this information without your consent if it is felt to be in you or others best interest and safety to do so.
- **General Data Protection Regulation (GDPR)** All of the data supplied (i.e. consent forms) will be kept in a locked filing cabinet stored within the Wrexham Maelor Gladstone Centre. All information will be held by Bangor University and Betsi Cadwaladr University Health Board (BCUHB).
- Any electronic data will be stored securely on a password-protected NHS device. Any audio-recordings of interviews will be destroyed upon Ronda Bell being awarded her doctorate.

If you require further information or have questions please contact Ronda Bell at [rmm20@bangor.ac.uk](mailto:rmm20@bangor.ac.uk)

Version 1. 04/2022.





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- All other data will be retained by the research team for a minimum of five years, after which they will be safely and securely disposed of, in line with NHS policies.
- Certain individuals from Bangor University and regulatory organisations may look at the research records to check the accuracy of the study. This information will not be identifiable and they will not be able to find out your name or contact details.

#### **What will happen to the results of the study?**

- The information collected will be written up in the form of a doctoral thesis, a copy of which will be available from Bangor University Library. The study may also be published in academic research articles and/or conference presentations. All information presented will be non-identifiable.
- There may be some direct quotations, but there will be nothing identifiable in these. If you decide to take part in the research study, a letter with the results of the study can be sent to you.

#### **What if I want to withdraw from the study?**

- You can withdraw from the study at any time before the research is submitted for assessment by emailing Ronda Bell ([Rnm20xky@bangor.ac.uk](mailto:Rnm20xky@bangor.ac.uk)). You do not need to provide a reason for doing so. If you withdraw from the study, all audio recordings, transcripts, and your data will be securely destroyed. None of your information will be used for the research.

#### **Who is funding and organising the study?**

- The research is organised and funded by the North Wales Clinical Psychology Programme at Bangor University.

#### **What if something goes wrong?**

- If you have any concerns about any aspects of this study you can speak to a member of the research team. They will do their best to address your concerns and answer any questions. You can contact Ronda Bell at [rnm20xky@bangor.ac.uk](mailto:rnm20xky@bangor.ac.uk) or Dr Rose Stewart at [rose.stewart@wales.nhs.uk](mailto:rose.stewart@wales.nhs.uk).

If you require further information or have questions please contact Ronda Bell at [rnm20xky@bangor.ac.uk](mailto:rnm20xky@bangor.ac.uk)

Version 1. 04/2022.



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- If you have contacted the above and are still unsatisfied with how your query has been addressed and/or you wish to raise a concern, please contact Huw Roberts, College Manager, College of Human Sciences, who is the Bangor University contact for complaints regarding research through one of the following: [huw.roberts@bangor.ac.uk](mailto:huw.roberts@bangor.ac.uk), +44 1248 383136.

**How do I volunteer to take part in the study?**

- If you would like to take part in this study, please complete the survey on: [xx]. Should you meet the criteria for our [study](#) and we have not reached capacity, you will be contacted by Ronda Bell to arrange a convenient time for the interview to take place.

**For further information on any aspect of the study please contact: Ronda Bell  
Trainee Clinical Psychologist, [rmm20xky@bangor.ac.uk](mailto:rmm20xky@bangor.ac.uk)**

**Thank you for taking the time to read this information sheet.**

If you require further information or have [questions](#) please contact Ronda Bell at [rmm20xky@bangor.ac.uk](mailto:rmm20xky@bangor.ac.uk)

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### Participant Consent Form

**Study Title:** Turning the T1DE: Recovery Factors in Type 1 Disordered Eating

**Please initial each  
box if you agree with  
the statement**

- |   |                          |
|---|--------------------------|
| 1. I have read and understood the information sheet for the above study. I have had time to think about it and ask questions. My questions have been answered to my satisfaction. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. This will not affect my medical care or legal rights.      | <input type="checkbox"/> |
| 3. I understand that I will be encouraged to contact my GP and/or a professional from my health team if the research team become concerned about my emotional wellbeing.          | <input type="checkbox"/> |
| 4. I understand that any information about me will be made anonymous before this study it is submitted for marking and publication.   | <input type="checkbox"/> |
| 5. I agree to my interview being recorded.  | <input type="checkbox"/> |
| 6. I agree to anonymous quotes of what I have said being used in publications   | <input type="checkbox"/> |
| 7. I agree to take part in this study.  | <input type="checkbox"/> |

.....  
**Name of participant**

.....  
**Date**

.....  
**Signature**

.....  
**Researcher**

.....  
**Date**

.....  
**Signature**

If you require further information or have questions please contact Ronda Bell at [rmm20xkv@bangor.ac.uk](mailto:rmm20xkv@bangor.ac.uk)

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### Participant Debriefing Form

**Study Title:** Turning the T1DE: Recovery Factors in Type 1 Disordered Eating

**Research Team:** Principal Investigator: Ronda Bell  
Chief Investigator: Dr Rose Stewart  
Academic Supervisor: Dr Mike Jackson

This study aims to explore the lived experience of individuals who either are in recovery or who have recovered from type 1 disordered eating (T1DE). We are hoping that interviewing people with lived experience will help us identify common factors and themes that have helped shape journeys to recovery. It is hoped that listening to these journeys will help us understand what recovery looks like in T1DE which can inform future interventions.

Whilst we hope that talking about your journey was meaningful and hopeful, we can understand that there might have been or still are distressing moments within your story. Should you feel you need further support, we have compiled a list of resources for you that you might find helpful.

#### **Specific Support for Diabetes:**

Diabetes UK provides a wide variety of resources to people living with diabetes. They also have specific page for individuals who experience difficulties with their eating. You can find further information about eating difficulties in diabetes by visiting: <https://www.diabetes.org.uk/guide-to-diabetes/life-with-diabetes/diabulimia>. They also have a helpline that you can ring at **0345 123 2389** should you require further support.

The JDRF website also offer further information at: <https://jdrf.org.uk/information-support/living-with-type-1-diabetes/health-and-wellness/type-1-diabetes-and-eating-disorders/>

#### **Support for Eating Disorders**

Beat are a UK eating disorder charity. They are a general resource for eating disorders and have a wide variety of resources available. <https://www.beateatingdisorders.org.uk/>

#### **Mental Health**

If you feel any further distress, the Samaritans are available 24/7 and can be reached by calling 116 123 or you can visit. <https://www.samaritans.org/wales/how-we-can-help/contact-samaritan/>.

**For further information on any aspect of the study please contact: Ronda Bell Trainee Clinical Psychologist, [rmm20xky@bangor.ac.uk](mailto:rmm20xky@bangor.ac.uk)**

**Thank you for taking the time to read this sheet.**

If you require further information or have questions please contact Ronda Bell at [rmm20xky@bangor.ac.uk](mailto:rmm20xky@bangor.ac.uk)

Version 1. 04/2022.

## Appendix D: Interview Guide

### Interview Questions Template

1. What does the word recovery mean to you?
2. What factors do you believe have contributed to your recovery?
3. What factors do you believe have hindered your recovery?
4. How do you think your views or beliefs have changed throughout your journey (i.e. with yourself and your relationship with diabetes)?
5. What do you think you'll need to bear in mind to protect your recovery in the future' work?
6. After having these experiences, what advice would you give someone going through a similar experience?
7. Is there anything else you want to share with me or think it would be helpful to know about your journey?

## Appendix E: Examples of Analytic Process: Memos and Transcript Sections

### Technology

Raw Data: *"The denial of technology were by far the biggest barriers"* -Participant 1

*"I mean, it took away the ritual and by I don't think I was using it appropriately, like I never skipped my insulin on it, but like some days I just wouldn't check it, but bear in mind before I had gone without any insulin, the longest I went without any insulin was 3 1/2 weeks. So nobody can tell me that putting me on an insulin pump, having it on in the background and not checking it isn't better"* -Participant 1

Memo: This person is really advocating for the use of technology. It feels like technology could help with recovery and could be listed as a recovery factor whereas the denial of technology is a barrier? I think this is something to look at in future interviews. I'm curious if there are any differing viewpoints here.

Raw Data: *"It does. It removes that thing, right, I've got to get a needle and do this for my tea. You know, you can just put press some buttons, and you've done it and it does...I worried, I know they debated whether I should have one at the time because I wasn't injecting and was making a right mess of everything, but, I'm so glad they did because it removed that decision from me multiple times a day."* -Participant 8

Memo: It feels like the pump is mentioned as a recovery factor again here as well. It appears to remove the trigger and therefore the individual is able to get the insulin they need, and the risk of omission is lower. This participant similar to previous participants discusses the struggle of possibly not getting a pump so denial of technology is coming up as a theme again. The statement seems really similar to what Participant 5 spoke about.

Raw Data: *"I would say technology has helped, but overall I guess probably hindered. Umm, I think back in 2019 roughly I just started to really, early in the year and started to close loop. So I was using technology a lot more engaged and a lot more, but it was quite intense and I was having to do a lot and think a lot and had someone trying to help me which was great, but um it was just it wasn't, it probably took up a bit too much time and energy and I think that's where I started to step away a lot more and be like I can't do this and I think that's where burnout occurred um and I would take regular pump breaks. So it was great, but I knew that I could just take the pump off and that was okay and then I would just forget about it. Umm so I think in that sense it's definitely it's been really helpful, but I think there is a technology burnout as well that sometimes it's just too much information. "*

*So I had access to technology on my wrist that I could just look at and be like, oh yeah, blood sugars are here, but then I've been in appointment maybe with my psychologist and I have*

*constant access, say if were more nervous or anything, I just look at it and so it's been great having more access to tech, but I felt that I'd become a bit too like, yeah it was just too much and too overwhelming, and it still is sometimes that I just like yeah, it's great to have the numbers and see where you are, but sometimes you're like oh my goodness please no because it's kind of just takes up too much brain space."* Participant 12

**Memo:** Another view is that technology doesn't always help and can lead to burnout. Other participants have mentioned the idea of diabetes distress/burnout as a risk factor so it appears technology can help and hinder. There also appears to be something about when people are giving technology in their journey. For some people taking off the pump and having a break from technology was seen as helpful and for others they know they can't do that or they risk relapsing. Ultimately it feels like an individualistic thing that differs for everyone and so important to present both sides in the recovery model.

### **Biological Factors-Pain**

**Raw data:** "when people would say Lantus hurts, I'm like it doesn't hurt, and it didn't hurt because I never used to take it, you know? But people always say, oh, I hate Lantus. They say it always stings. Like I didn't used to think it stung like that." -Participant 2

**Memo:** It appears there's the physical pain of needing to inject that can put people off recovery and act as a barrier to recovery. We didn't go into the specifics on pain, but I'm curious if this a continuous thing or as a result of not taking/reducing insulin for a certain period of time? i.e. is it specific to insulin omission.

**Raw data:** "No, it was never ever told it was never told to me about the insulin resistance thing. I was never told about the insulin resistance thing and I was never told about like my leg. Like the leg pains, the nerves waking up again um and a few other things, but I was never told about the emotional effect it has on you and your brain. I was never told about insulin resistance. I was never told that, you know, things won't move faster, yeah none of that was ever explained to me." -Participant 7

**Memo:** I'm not sure if this participant was talking about the same thing as participant 2? It sounds like a different type of pain which sounds more intense. I need to find out some more information about this process, I'm limited in my own experience of these concepts. I don't want to assume it's just the 'typical' pain of injecting, especially considering it sounds like more. Additional pain like this could be a massive barrier to recovery so I need to look into this in the next few interviews.

**Raw Data:** "Umm, I'm trying to think of what else. You need to do it slow because after not having insulin for so long and then you go back to giving yourself insulin, you can get like insulin-neuritis. So when I started giving insulin, I'd have like neuropathic pain, retinopathy, and stuff, so yeah slow is definitely better" Participant 9

**Memo:** I need to ask Rose about some of these concepts as I'm not familiar with how they would impact on recovery. Message from Rose: "I've definitely come across the thing about a fast reduction in HbA1c damaging eyesight, but hadn't come the neuropathy one before. I've done some research and it definitely is a thing where the nerves get inflamed by insulin in people who've been running high for ages, and it's called insulin neuritis (paper here: Treatment-induced neuropathy of diabetes: an acute, iatrogenic complication of diabetes | Brain | Oxford Academic (oup.com)). A diabetes consultant reckons it's transient and should go after a few months, but can feel pretty unpleasant while it's around. It sounds like quotes 1 & 2 are talking about this, whereas quote 3 is talking about insulin stinging"

After hearing from Rose, it's really made me think about how important this would be, in being told these would be things to expect. Some previous participants mentioned how they weren't informed about biological changes and I think this would fit nicely under that.



## Appendix F: Table of Codes and Additional Quotations

The table below shows a list of codes generated from the data and a sample of quotations. The selected quotations may not represent every initial code listed and is only a sample.

<b>Readiness to Change</b>	
<p><u>Rock Bottom</u></p> <p><i>(Hitting a 'rock bottom'-losing people, losing everything, losing career, inpatient admission (moment of need to change, realisation); passing up career opportunities; physical health deteriorating, inpatient admission; worried about further health complications)</i></p>	<p><i>"What's driving it is the fear that I'm not gonna be able to get out of bed in the morning and do my job, and I'm gonna lose everything. You know, like, and I've lost everything on several occasions with my life. I do not want to do that again." – Participant 1</i></p> <p><i>"I think initially being told that we um would feel an inpatient admission would be suitable for you. Umm and then mm yeah, I think that was a key moment."-Participant 12.</i></p>
<p><u>Identifying Values</u></p> <p><i>(Having Career Opportunities-Values; children/family, friends, wanting to start a family; doing it for someone/something else, not feeling it was worth it; wanting to start a family; social services taking children away; doing it for others; not wanting others to worry)</i></p>	<p><i>"I think it was having so many hospital admissions that umm like each time I had been to hospital, I'd be there bit longer each time because I was taking longer to get ready and to get back to myself and that having such a big impact on my kids. So I needed to like keep things stable at home for them." -Participant 3</i></p> <p><i>"Yeah. So I think for me, it was about my relationship with my my wife. And um you know, she she's had to go through that with me as well. And and just seeing her sort of breakdown and say to me like, I worry that every night we go to bed, you're not gonna wake up the next day and, you know, we got married and then this happened yeah and I worry that it is the fact that we got married that all of these sorts of these things started to happen um and it was very much my relationship with my wife and I didn't wanna lose that." Participant 7</i></p>
<p><u>Insight</u></p> <p><i>(Not realising it was an eating disorder; insight Refusing Support; Not realising it was a problem; Lying to people; not doing it intentionally; didn't want to accept there was a problem; difficulty asking for help, family or</i></p>	<p><i>"So it was sort of that pivotal moment of her having a sort of breakdown in terms of, you know, expressing to me what her thoughts were around it and how upset and hurt she was. I mean, obviously I realised that while it was happening that I was obviously hurting her, but I didn't realize because your eating disorder kinda takes over your brain. So you, you know, I didn't</i></p>

<p>friends asking me, professionals bringing up the topic)</p>	<p>particularly realize how much or how significantly it was hurting her. So yeah, it was definitely sort of that moment of I need to do something if I want to save this.” Participant 7</p> <p>“I think first (first step) admitting that there's a problem. I didn't admit there was a problem for a long time.” - Participant 7</p>
<p><u>Hope</u></p> <p>(Possibility of Recovery; Knowing it's possible; Realising change is possible, Hope about the future)</p>	<p>“Believe that there is another side. That there is a way out” -Participant 1</p> <p>“I think in terms of knowing that recovery is possible, there's definitely a need for that” - Participant 2</p>
<p><b>Risk Factors</b></p>	
<p><u>Diabetes Distress and Burnout</u></p> <p>(Demands of managing diabetes, considering medical perspective and demands of managing diabetes, experiencing distress when having to eat during hypos, experiencing technology burnout.)</p>	<p>“but it you know, adds to the mental burden, isn't it, that you know what your blood sugar is every moment of the day so you just can't ever forget about diabetes. Every moment of the day. So you just can't ever forget about diabetes.” - Participant 10</p> <p>“I think initially like trying to work through, say burnout was a big thing for me so I'd feel like I'd get very burned out with diabetes and I'd want to kind of feel like I'd need to stop, I'd just need a bit of a break, and then that break turns into a few days which would then turn into a few weeks.” -Participant 12</p>
<p><u>Nature of Diabetes</u></p> <p>(Restricted Eating, having to inject insulin, needing to count carbs, needing to be aware of nutritional labels, diabetes management involving elements of disordered eating).</p>	<p>“I was like, oh shit, numbers, bingeing, mood dictated by the scale, fuck I was back in eating disorder territory.” -Participant 1</p> <p>“You know, and um so I'm pretty sure that it was the sort of having to count things,,“ –Participant 11</p> <p>“If you look at how you manage type one diabetes, you are almost boxing up an eating disorder.” -Participant 2</p> <p>“A lot of the behaviours that I have to do to maintain well-controlled diabetes are eating disorder behaviours. So I have to check food packets, look at carbohydrate counts, you know,</p>

	<p><i>check protein counts, fat content just, you know, certain foods that I don't tend to eat very often because it's just really annoying because I know my blood sugars will be on a roller coaster after going up and down. So I think, I'm not sure I will ever have 'normal' eating because I just don't think it's part of life with type one diabetes, but I'm the closest to recovery.” -Participant 10.</i></p>
<p><u>Previous Psychological Difficulties</u></p> <p><i>(having low self-esteem, experiencing depression prior to developing an eating disorder, being a perfectionist, previously experiencing an eating disorder before diabetes, control being taken away or decisions made on their behalf, ACEs, having family difficulties, being in a cycle of guilt/shame around diabetes management, experiencing trauma.</i></p>	<p><i>“I've put about, I'm a bit of perfectionist anyways, and diabetes management demands perfectionism, really, but that's really what they're asking for you in clinic, especially at pregnancy, because the targets are so tight and that sort of can lead you into quite unhealthy, like black and white thinking” -Participant 10.</i></p> <p><i>“The other thing was and this is weaved through the whole story is that when I was being forced to eat what was on that print out on my mother's fridge, I became at least 2 1/2 to 3 stone overweight and remember I was a child, so the consequence for me and I was I was told off for being fat and yet I was having this food that I was told...basically I was naughty if I didn't eat and I was naughty as a result of eating it. That's like a perfect storm. There is no escape from that other than getting on a bus and running away.” - Participant 6</i></p>
<p><u>Significant Changes in Life</u></p> <p><i>(Difficulties arising when going to university, pregnancy-post birth, relapsing after pregnancy, being part of the LGBTQI+ community and experiencing difficulties with sexual identity family support breaking down, going through menopause, going through puberty, moments of major life stressors where there is a lot of change).</i></p>	<p><i>“Obviously you have to have good diabetes control when you're pregnant. And even with good control I had, I had a premature baby. She's fine now, but like that isolation and uncertainty like being in hospital by myself, lockdowns, so no visitors, relationship breaking down, and then just difficulties after birth, like I resent diabetes for not be able to like breastfeed because she was early and sleepy and stuff. And then I think that everything that happened caused like depression after she was born which made me not care about myself, but then there's like self-esteem issues there from. Relationship</i></p>

	breakdown. It all just started at the same time.” -Participant 3
<b>Roadblocks</b>	
<p><u>Lack of Knowledge</u></p> <p>(Feeling alone/isolated and not knowing others experiencing this, not wanting to come forward due to feeling alone, not knowing what needs to be done or how to change.)</p>	<p>“You know, when I was diabulimic, I knew that other people must do what I do to lose weight. I knew I knew that other people must do that, but I thought I was the only person on the planet stupid enough to do it to the point where I was in hospital, right. Like I thought other people, they probably did this, but they may just do it to get into the dress at the weekend or something. You know, like I thought I was the only person crazy enough, stupid enough, to take it to the point where I was risking my own life.” Participant 1</p>
<p><u>Systematic Issues Getting in the Way of Changing</u></p> <p>(Not being believed; Lack of support for people who find themselves in the middle ‘not too risky, but appear they’re doing okay’; Support not available when needed; Lack of treatment; unhelpful therapy; therapy not relevant to physical health; unhelpful comments made by clinicians; language used in clinics ‘noncompliant’; not informed about impact diabetes would have on mental health; Not being diagnosed; financial concerns-time off work; being blamed; feels like trial and error (no designated treatment plan); Shame of having an eating disorder; shame of having diabetes; shame; stigma; unsupportive relationships; financial opportunity; not having treatment/formal therapy; Not having a diabetes psychologist/accessibility of the service; not getting on with the chosen therapy approach; lack of patient centred care; eating disorder services not prepared for diabetes; not meeting ED service criteria; lack of patient centred to care; being told it doesn’t exist; no offering of psychology at clinics; progress not being monitored; having out of date information still being provided; experiencing difficulty relationship with professionals; lack of face to face support after covid; experiencing poor care; normalisation of dieting; clinic feeling like a tick box exercise, feeling dismissed, being seen too quickly/not having the opportunity to discuss difficulties; not feeling comfortable bringing up</p>	<p>“Yeah and that's the other, obviously yeah problem with this, is that the help isn't there. I mean I like I said, I'm very lucky. I go to a hospital that does have a type one eating disorder service, but I know throughout the country there isn't that. I mean, hopefully more people now that it's obviously passed the national pilot and hopefully you know people, hospitals will be getting more money and disorder service sort of specialities yeah, but I'm very lucky in that case, but there's only a small amount that they can do if they don't have the funding and all of that, it's about having the correct services there to help people.” - Participant 7</p> <p>“I feel like when I was trying to open up to my doctor and my doctor just wasn't. They, like, wasn't interested. It felt like it was about you look fine and your BMI and everything is fine. You're, everything's fine. All you've got is a complication. It was as if it was just like. He looked at me as if I was a picture of health, but when I was trying to tell them what the problem was, it was, he just wasn't listening. And I think that's where it became difficult because I couldn't find the person that's supposed to help me through this condition and help me through the journey and get into where I needed to be. I didn't feel like I could get him to buy any of what I was saying that was a problem for me and I think that I found it difficult to discuss that and I think it that it still took some time for me to open</p>

<p><i>the topic; not being asked; professionals not having the knowledge; triggering media; restricting of technology; feeling powerless; healthcare professionals denying the difficulty; negative views of the NHS; not being offered therapy; not having time; having to recover on own; difficulty with work/employer; being able to lie in clinic; having to recover on own; constant fighting to get support; link between unhealthy behaviours and good blood sugars being reinforced; discrimination against body types/differences/bmi in the ED services; long waiting times for services; professionals not communicating between each other or between services; having to speak up for yourself to get support; professionals being patronising; continuity of care; preferences not being respected; nature of clinic-not feeling good enough; nature of clinic-feel there isn't enough time to discuss concerns, inconsistency; system propelling perfectionism)</i></p>	<p><i>up to a diabetic specialist nurse about it.”- Participant 5</i></p> <p><i>“I'd have hospital admissions, the diabetes nurse stopped visiting me because I heard one of the doctors in recess, I was like, half asleep. I heard them saying, like, oh, we'll probably struggle to get the DSNs to her because they're at their wits end because she's just noncompliant. Umm. They didn't wanna help me.” -Participant 3</i></p>
<p><u>Psychosocial Factors getting in the way of Change</u></p> <p><i>(breaking down; feeling angry; stigma, shame, avoidance; not seeing immediate change (delayed gratification). Not feeling safe --Not feeling psychologically safe to share details; not feeling supported)</i></p>	<p><i>“I think it was the shame of people looking at me and realizing that I had diabetes because I didn't want people to know that I was diabetic. And I think that's where it was for me. That's where it was at, is all that misinformation and knowing that people make assumptions because there's so much publicity around about it. And like all the nations that get more diabetics because of obesity. When an actual fact is that a majority of diabetics, aren't actually obese and we are in a normal body weight range. And even if we have, even if we are overweight, it wasn't our fault, it was our body attacked itself and stopped cells from producing what our bodies needed to function. And I think it was a lot of shame about the condition and bad publicity from press outlets.” -Participant 5</i></p>
<p><u>Physical Effects</u></p> <p><i>(Having cognitive fog; Pain when injecting long-acting insulin; weight gain; side effects of recovery; co-morbid conditions (for example-gastroparesis-affecting eating patterns); inhibited response to hunger cues, needing to eat more when experiencing a hypo; feeling tired)</i></p>	<p><i>“No, it was never ever told it was never told to me about the insulin resistance thing. I was never told about the insulin resistance thing and I was never told about like my leg. Like the leg pains, the nerves waking up again um and a few other things, but I was never told about the emotional effect it has on you and your brain. I was never told about insulin resistance. I was never told that, you know, things won't move faster, yeah none of that was ever explained to me.” Participant 7</i></p>

<b>Recovery Factors</b>	
<p><u><b>Psychological Recovery Factors</b></u></p> <p><i>(Acceptance- Accepting ups and downs; Recovering Cognitively; Accepting Thoughts; acceptance of weight gain; accepting weight gain is part of recovery/not as bad as you think; not acting on thoughts; accepting condition; relationship with food changed; health relationship with food; not acting on thoughts about insulin omission; accepting diabetes; acceptance that there will be change and this will be uncomfortable; Accepting there's a problem; accepting things need to be different; denying complications will happen to you; being in the right mindset; being open to changing</i></p> <p><i>Living in line with values- Living a meaningful life; Having other priorities; Having Accountability; meaningful activity</i></p> <p><i>Developing Alternative Coping Strategies- Developing alternative strategies in dealing with diabetes distress; having a 'new self'; healthy exercise; meditation, mindfulness, emotion regulation; recognising all or nothing thinking, breaking up routines, practicing gratefulness; changing mindset around food</i></p> <p><i>Self-Compassion- Stop comparing to others; self-compassion; being less self-critical; views changing about self and what they feel capable of; confidence strengthening; feeling empowered, feeling they know what they're doing; shift in self-worth; forgiving self; views about self changing (body image changing); feeling good enough, Feeling more comfortable within skin (confidence?), feeling stronger)</i></p>	<p><i>"Um I think in order to recover, I think I knew that I had to gain some weight and so I was fearful of that so I just had to come to terms with that and." -Participant 10</i></p> <p><i>"I don't think many of my beliefs have changed. I still like, for example, the classic one is, you know, insulin makes you put on weight like I don't think that belief has changed. I just think my reaction to it is slightly different because you when you sort of go into recovery, you have to accept that these things are going to happen. So it's more about not the beliefs changing, but more of an acceptance of certain things and they're gonna happen no matter what you do and I think that that's more the focus, it's about not necessarily like I said, changing the beliefs, it's about accepting the things that you know to be true and just trying to find a way to deal with them." -Participant 7</i></p> <p><i>"Like literally, hour by hour, sometimes and holding on to you know these thoughts and feelings don't last forever, but if you act on them, it doesn't get you anywhere. It just makes you more sick. You don't think it or feel it necessarily, but it does, and it doesn't, it's not worth like the you don't get the benefits from it, the risks far outweigh the benefits from it.." - Participant 12</i></p> <p><i>"So yeah, I try to be more kind to myself, I still don't get it right and you know, it is still incredibly hard to deal with, but I try and I always try and look like look at everything, no matter how small, no matter how big it is, as a series of hurdles and yeah rather than a barrier and a block, and sometimes it's harder to find the things you need to get over the higher hurdles or whatever, but there's always a way." -Participant 2</i></p>
<p><u><b>Social Recovery Factors</b></u></p> <p><i>(Peer Support; good relationship with professionals; positive relationships; telling people around you; feeling supported; feeling cared for; having a supportive partner;</i></p>	<p><i>"Umm yeah, I think it's really important to be able to have access to...so we've got peer support in our area which has been really helpful knowing that you're not necessarily on your own there are people that you know still go through this." -Participant 12</i></p>

<p><i>supportive family; supportive friend; having an outlet; sharing with a friend; not keeping it a secret; not hiding emotions from others; speaking up and sharing story; letting professionals in; asking for help; beneficial talking about it; needing to share the problem, having accountability (sharing their story with others). Social Media/Peer Support; Having Peer Support; having a shared experience; feeling invalidated leading to relapse; feeling non-judged and non-shamed; having an explanation for what was happening; feeling understood, advocating for others)</i></p>	<p><i>“Just the fact that people understand like you never can understand what it’s like unless you’ve been through it, especially with type one diabetes generally as well because you know it is such an all-encompassing condition and then you have disordered eating on top of that um there’s an element that people say, oh, you know, when you get type one, you automatically have disordered eating anyway, but when you have the more severe side of it and you know, grows into a proper sort of eating disorder um I think having other people who understand that um is really helpful and also they can give you like tips about what helped them and you know what the side effects “ -Participant 7</i></p>
<p><b><u>Biological Recovery Factors</u></b>  <i>(Being told about negative sides of recovery, being told what to expect when recovering; being told that things might get worse before better; availability of information online, being told about negative effects of increasing insulin too quickly, being informed about hormone changes and how they affect physical health, knowledge about nutrition, information on complications)</i></p>	<p><i>“I find that some HCPs don't want to tell you like what you actually physically go through. I mean I was very lucky with my consultant who retired. Before she retired, I asked her the question like to be totally honest and tell me what happens and she like walked me through step by step so I knew exactly what was to be expected, but other HCP's have not been so forthcoming about the information about what actually happens to your body when you start taking insulin again. And all that sort of stuff.” -Participant 7</i></p>
<p><b><u>Systematic Recovery Factors</u></b>  <i>(Positive Relationship with a Healthcare Professional- Positive relationship with a professional; appropriate language being used; being open with your team; feeling heard; listening to professionals; feeling empowered; having a good relationship with the professional team; need for external support; professionals asking questions; being treated as an equal; Pacing; feeling progress is being made; celebrating victories; spending energy wisely; feeling progress is being made; pacing self when recovering; not moving too quickly; celebrating the wins; being treated as an equal</i></p> <p><i>Bespoke treatment planning; MDT approach; having therapy; different modalities on offer; being given choice; personalising clinic; personalised support plan; bespoke plan</i></p>	<p><i>“She's been amazing. She hasn't even been around, like in my journey for that long, but yeah, she's made a big impact.” -Participant 3</i></p> <p><i>“For me, my nurse was, I think my nurse basically saved my life because she listened.” - Participant 5</i></p> <p><i>“But it is different now, I have a really good relationship with my diabetic nurse and she's super supportful, but I don't know if that's just because of everything that I've been through, whether they like, you know, feel like they need to give that extra support, whereas it should be there from the start really.” -Participant 9</i></p>

<p><i>Removal of tech or adding of technology; technology removing choice of omitting insulin; technology used as a tool to improve understanding/knowledge; technology removing shame/stigma-injecting in public; feeling more in control with the help of technology)</i></p>	
<b>Relapse</b>	
<p>Growth during Relapse</p> <p><i>(Importance of recognising triggers, returning back to recovery, not being the same journey, learning from previous mistakes, reflecting on the journey, doing things differently next time, reminding self of progress made)</i></p>	<p><i>“but I am aware that, you know, it's probably a relapsing remitting condition. So you know under periods of stress likely the first thing to go is going to be my eating is gonna go, you know up the creek.” - Participant 10</i></p> <p><i>“but there could come a point where I'm back in recovery mode because I need to find a solution to a problem that's restarting or retriggering for me, but for me I would probably say I'm more recovered than recovering.” -Participant 5</i></p>



### **Chapter 3: Contributions to Theory and Clinical Practice**

## **Contributions to Theory and Clinical Practice**

This thesis explored the impact that psychosocial factors have on people living with type 1 diabetes. Firstly, the systematic review focused on the effects of shame on the management of type 1 diabetes. The empirical paper explored the concept of recovery and recovery factors in type 1 disordered eating (T1DE). The purpose of this chapter is to build upon the discussions presented in the aforementioned papers. It will provide additional discourse on the implications for clinical practice and contributions to theory resulting from the research conducted. Additionally, this chapter will include a reflective commentary on personal reflections on the research process.

## **Contributions and Implications for Future Research and Theory Development**

### ***Systematic Review***

The systematic review was the first to the author's knowledge to review the literature on stigma and the management of type 1 diabetes whilst following PRISMA guidelines. This review was, therefore, able to contribute a review of the literature that was useful in consolidating results and identifying gaps that were previously unidentified. Results of the systematic review highlighted that there was an association between stigma and the management of type 1 diabetes. Although causality could not be determined due to the cross-sectional nature of the studies, the consistency of findings found, as well as results from qualitative research, support the idea that a negative effect is likely. A major strength of this review was the consolidation of studies from multiple countries and areas, indicating that although the concept of stigma may be experienced differently, it is a phenomenon that is shared globally.

This review adds to the growing body of research on the construct of stigma. The concept of stigma is complex and multifaceted with several psychological theories proposed

to make sense of this process (Sheehan et al., 2022). The review briefly touches on Goffman's (1963) understanding of stigmatisation and explains how stigmas are constructed from social identities that do not match with our own. The results of this review can be further explained by additional parts to Goffman's theory (1963).

Goffman's (1963) paper on 'spoiled identities' describes how when individuals are stigmatised, they engage in a process of 'stigma management'. This means that individuals who are stigmatised may use specific strategies to avoid further stigmatisation. These strategies may involve concealing a stigma from others either directly by hiding it or by controlling the narrative surrounding it either through nondisclosure or by educating others. Individuals may also engage with 'stigma solidarity' which is when individuals who are stigmatised form relationships with each other for support. All of these strategies were found within the systematic review and some were also found within the empirical paper. For example, the review highlighted that individuals will attempt to make their condition less visible by hiding their injection of insulin or hiding their diabetes devices from others. The review also highlighted that individuals may avoid disclosing the fact they have diabetes to others to avoid stigma. In regards to further research, this review has also highlighted the need for a better understanding of the interventions that may be needed to address the issue of stigma. Given the complexity of the area, it is likely that both individual and systemic interventions will be needed. A different systematic review on interventions to reduce shame outside of diabetes found that a wide array of interventions, such as cognitive behavioural therapy, mindfulness, interpersonal therapy, group therapy, family therapy, expressive arts, and community-level interventions, can be effective in reducing shame (Goffnett et al., 2020). It would be helpful for further research to look at how effective these interventions are for someone living with type 1 diabetes and experiencing shame as a result.

In addition to the above, this systematic review has highlighted the lack of research on intersectionality within type 1 diabetes. This supports findings by Turan et al., (2019) that intersecting stigmas are often studied in isolation, which is unrealistic as individuals are likely to experience multiple stigmas simultaneously from different areas. Research on the relationship between intersectional stigma and health outcomes found that intersectional stigma is negatively associated with poorer health outcomes (Turan et al., 2019) and highlights a need for further research to be conducted in this area.

Within the systematic review, only one study directly referenced the idea of intersecting stigmas, and a few additional studies briefly mentioned how stigma varied between sexes. Within the empirical study, a few participants who identified as being part of the LGBTQI+ shared that they faced additional stigma due to their sexuality. They also reflected on how they felt this played a role in their risk of developing and experiencing type 1 disordered eating (T1DE) and increased their distress levels. Despite being an important area to focus on, limited research has looked into this, and it is hoped that both of these papers have hopefully contributed positively to the evidence base.

### *Empirical Paper*

This study was the first known qualitative study to explore the concept of recovery from T1DE within the United Kingdom. Results from the empirical paper indicated that recovery is a non-linear process that is shaped by systemic, psychological, social, and biological factors. This paper also identified the barriers to recovery as well as briefly touched on the factors related to change contemplation.

Some aspects of this model align with the ‘Stages of Change Model’ (Prochaska & DiClemente, 1983) which is a transtheoretical model to explain an individual’s readiness to change. The ‘Stages of Change Model,’ presents six steps: precontemplation, contemplation,

preparation, action, maintenance, and termination. Within the precontemplation stage, an individual initially may not realise they want to change or realise their behaviour is problematic. However, after assessing the pros and cons of changing makes the decision to change and enters a contemplation stage. It felt that this describes the process of 'readiness to change' that was identified in the recovery model for T1DE.

Throughout the study, participants described shifting from denying their condition to becoming more aware of the effects Type 1 Disordered Eating (T1DE) had on their quality of life which helped them to start to move towards change. However, this did not appear to be a straightforward process, with many participants describing that it sometimes took multiple attempts for them to accept that they had an eating disorder and attempts by others to convince them otherwise did not always help.

One study examining the perceived barriers towards help-seeking behaviour for eating disorders found that the second largest barrier to coming forward for help was denial or failure to perceive the severity of the condition (Ali et al., 2017). Furthermore, an audit of appointments in an eating disorder clinic in London found that 26% of new patient referrals do not attend their first appointment, and 23% attend only once (Leavey et al., 2011), highlighting a clinical need for research to be conducted in this area.

A review on improving motivation to change amongst individuals with eating disorders found that a range of interventions can be effective at improving motivation to change (Denison-Day et al., 2018). However, there is a lack of research on how effective these interventions are at improving motivation in individuals with T1DE. Research has shown that there are differences in motivations to change between patients with anorexia nervosa and bulimia nervosa (Casasnovas et al., 2007). Given this, as well as the differences between T1DE and typical eating disorders, research needs to investigate this area more fully.

The Stages of Change Model (Prochaska & DiClemente, 1983) also aligns with this study's concept of relapse. The TIDE recovery model, proposes that risk factors have the potential to overwhelm the maintenance cycle and take a person out of the recovery maintenance phase. We also propose that relapse should be seen as a learning opportunity, a chance for individuals to reflect on what triggers led to relapse to prevent this occurring in the future. These concepts are also addressed within The Stages of Change Model (Prochaska & DiClemente, 1983) which explains that an individual within the maintenance stage may slip back into the contemplation stage if they are faced with a stressful situation. It also agrees that relapse is not a sign of failure, but a part of the change process. Some of the recovery factors suggested within the TIDE recovery model may also be transferable to individuals with eating disorders (EDs) outside of type 1 diabetes. Currently there is a move towards adopting a more personal recovery framework for EDs and moving away from symptom-focused recovery presented within a medical model (Wetzler et al., 2020). A personal recovery framework is particularly interested in a more holistic approach to measuring recovery (i.e. the social, psychological, emotional, behavioural, and physical factors) as opposed to focusing purely on measuring changes in symptoms. However, this is still a relatively new concept and limited research on personal recovery for EDs exists (Wetzler et al., 2020).

One example of a personal recovery framework is the CHIME model (Leamy et al., 2018). This model was created from a systematic review of the literature on important factors relevant to recovery in mental health. It proposes five key factors that are essential for recovery: Connectedness, Hope and Optimism, Identity, Meaning and Purpose, and Empowerment. It was felt that the recovery factors identified within the TIDE model align with these categories. For example, when defining recovery, many of the participants spoke about the need for hope that recovery was possible and how this alongside identifying their values moved them towards change. They also spoke about the importance of having positive

relationships which could be explained by the ‘connectedness’ category within the CHIME model. This further contributes positively to recent research that indicates that a personal recovery framework may be useful in understanding ED recovery (Wetzler et al., 2020).

### **Implications for Clinical Practice**

This section of the paper will focus on the implications this research may have on clinical practice. It is important to note that all suggestions are made in light of the limitations of these studies, as well as an acknowledgement that this topic is still widely under-researched.

#### ***Psychological Need***

Both papers support the need for psychological support within diabetes services. Within the systematic review, a negative association was found between stigma and the management of type 1 diabetes, highlighting that stigma impacts on the uptake of technology, avoidance of self-care activities, help-seeking behaviours, and system-wide barriers. The empirical paper explored the concept of recovery and found that recovery is made up of a combination of psychological, social, biological, and systemic factors, with psychological concepts such as self-compassion, acceptance, emotion regulation, and values-based work being reported as helpful concepts for the recovery process.

This research adds to the growing body of evidence that indicates that people with diabetes who have poorer mental health experience poor self-management and blood glucose levels (Askew & Solomons, 2019; Gonzalez et al., 2008). According to the *Too Often Missing Report* (Askew & Solomons, 2019), 70% of individuals living with type 1 diabetes said they felt overwhelmed by the demands of their condition, with 75% of these people saying they felt their self-management was affected by these struggles.

Despite these findings, 75% of people with diabetes felt they needed specialist support that they could not access (Askew & Solomons, 2019). Furthermore, multiple participants in the empirical study reported that they did not have access to a diabetes psychologist and reported that they felt that psychology would have been helpful in their recovery journey. It is hoped that both the systematic review and the empirical paper will positively contribute to the research in this area to further the drive for psychology within diabetes services.

In addition to a lack of psychological provision, there is also a lack of evidence-based psychological interventions for people living with diabetes and even more so for individuals living with T1DE. As mentioned in the empirical paper, participants in the study explained psychological concepts that were helpful, such as self-compassion, emotion regulation, and acceptance, that are in line with third-wave therapy approaches. Therefore, this paper has been able to point towards psychological interventions may be useful for this population. Finally, this paper also presents a recovery model that can be used as a formulation tool for both individuals and teams.

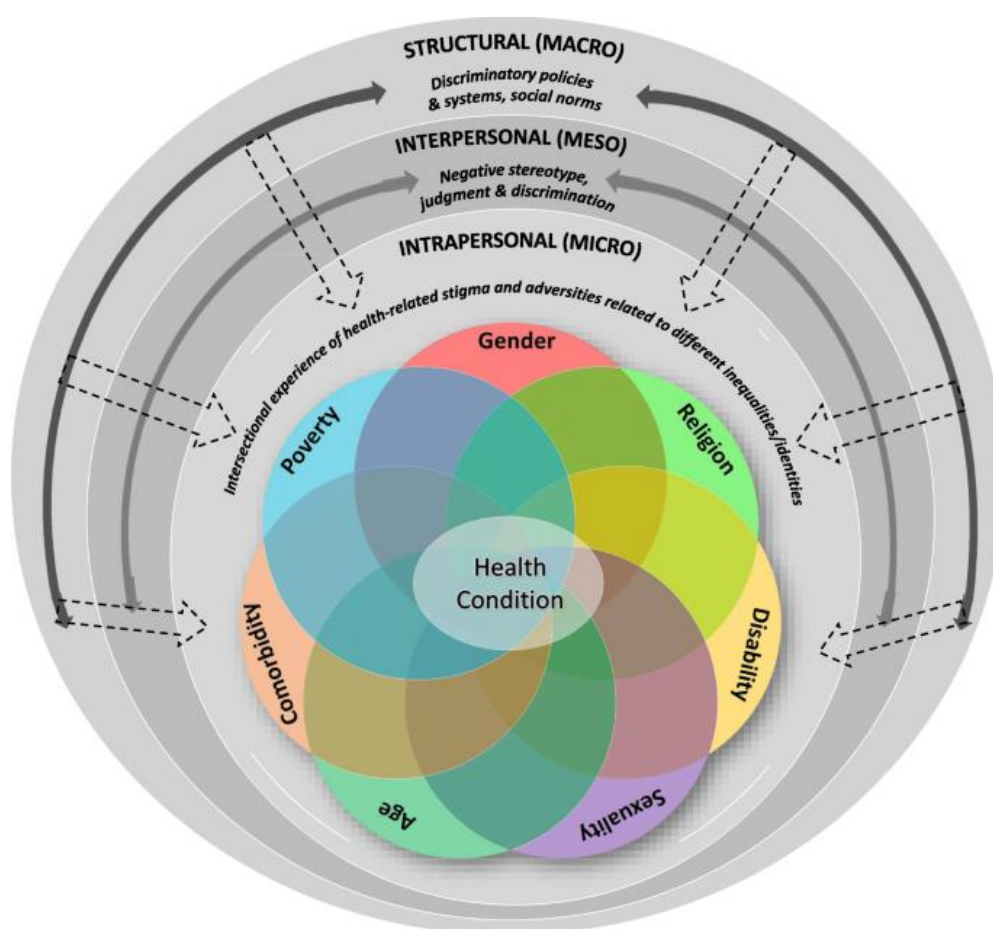
### *Systemic Issues*

On a systemic level, collectively, both papers highlighted the need for wider-based interventions to work on concepts such as de-stigmatisation, language use, clinic structure and generally for diabetes services to be psychologically informed. First off, the systematic review highlighted how detrimental stigmatisation can be in the management of type 1 diabetes. Furthermore, many of the participants in the empirical study reported on how stigmatisation and shame acted as barriers to seeking help. As previously mentioned, both papers found a link with intersectional stigma.



The concept of intersectional health-related stigma can be further understood with a model created by Rai et al. (2020). Figure 1, taken from Rai et al. (2020), illustrates how intersectional identities are layered to understand how they interact with each other as well as with the individual's physical health condition. This model proposes that there are different levels of stigma that an individual faces. The 'Macro-level' refers to policies and practices within structural systems that can lead to stigma. The 'Meso-level' refers to the judgements and discriminations an individual faces. These are similar to the concept of 'enacted stigma' that was discussed within the systematic review. Meanwhile, the 'Micro-level' is related to the concept of 'felt stigma' that was mentioned in the review and experienced by feelings of shame, guilt, and fear of judgement from others.

**Figure 1.** Model of Intersectional Health-Related Stigma (Rai et al., 2020)



There are different ways an intersectionality can impact physical health conditions. In one process, the experience of being ‘double burdened’ by two separate stigmas can occur. For instance, in the systematic review, one study (Mencher et al., 2022) indicated that Black adolescents were concerned with being stigmatised and bullied due to their diabetes. This would draw further attention to their status as Black adolescents within a white-majority community. Intersectionality may also be experienced in relation to adversities that may be experienced by the identities they hold. As a result of these adversities, their healthcare may be affected—for example, participants living in poverty within healthcare systems where they need to pay for treatment.

Trying to understand how intersectionality plays a part within diabetes services and the management of diabetes is an important aspect of understanding how to ensure services are more accessible. For example, in the Mencher et al. (2022) study, Black adolescents were shown to decline diabetes devices because of intersecting stigmas. If this area is explored further, more can be done to improve the accessibility of diabetes technology. Furthermore, understanding the complexities that individuals are dealing with whilst managing their diabetes may contribute to diabetes professionals being more compassionate. Within the empirical paper, many participants reported experiences where they felt invalidated and unheard by their professionals. Some reported that they felt that they were seen just as numbers due to the nature of clinics. If more can be done to increase the understanding and compassion of healthcare professionals then individuals may trust their teams more and come forward with difficulties, resulting in better health outcomes.

Other systematic factors identified from this research include how language was used and how clinics were structured. Participants in the empirical study shared that when navigating relationships with their diabetes professionals, language was a big factor in participants either feeling validated and heard or stigmatised and judged. Notably,

participants spoke of the issues with the term ‘control’. They shared how they were often told they had ‘poor control’ or ‘good control’. These findings were in line with other research studies looking at the impact of language within diabetes settings, which find that using terms around control can lead people to feel guilty, anxious, or frustrated (Speight et al., 2021; Lloyd et al., 2018). The current empirical paper adds to this evidence base and highlights additional issues with using the word ‘control’ around individuals with an eating disorder. As one of the functions of an eating disorder can be around control, a person may feel additional levels of distress if told they have ‘poor control’.

This research adds to the growing evidence base to drive change for diabetes teams on a systemic level. Generally, it is hoped that this research is viewed and shared amongst healthcare professionals working within diabetes services. Hence, they become more psychologically informed on not only the issues surrounding stigmatisation and language but also on the other clinical issues that were highlighted within the empirical paper, such as the impact of clinic structure. Within the empirical paper, participants spoke about how unhelpful clinic structures were regarding reviewing blood glucose levels and feeling that this further fuelled perfectionistic tendencies. It would be useful for professionals to work with experts who have experience in how the structure of the clinic could be more user-friendly and compassionate. This is similar to how new policy documents on language use in diabetes have been created (Lloyd et al., 2018).

### ***Instilling Hope and Individual Recovery***

Lastly, some of the participants in the empirical paper spoke about the concept of ‘hope’ and how useful it was in their recovery to know that recovery was possible. Other participants reported that when they set out to recover, they were unsure of where to start. This study may give healthcare professionals some ideas of areas to mention with their

patients if they come across someone struggling with T1DE. As the topic of T1DE has only recently gained traction, little is known about what is currently helpful for this population. This paper will hopefully provide professionals with additional knowledge and confidence that recovery is possible. To make this more likely, both, the systematic review and the empirical paper have been put forward for publication. The results have also been communicated to a national steering group and shared with other health professionals working in the field. Lastly, the empirical paper has been submitted to a major UK conference for diabetes professionals.

It is also imagined that this research will be shared not only with healthcare professionals but also with individuals living with diabetes. When writing this thesis, attempts were made to ensure that the language used was accessible to both professionals and those living with diabetes. It is hoped that the findings of this study will also be shared with individuals living with T1DE and that this can start to provide hope that recovery is possible and will offer some suggestions on where they can begin. Due to the limitations highlighted in chapter 2 involving the lack of diversity within the sample, the next step with this model will be to review it with more diverse and marginalised participants to understand the generalisability of the findings. Should that be successful, we would hope to see this model created into self-help materials that may be used for those without access to psychology. This could also be further adapted as a learning resource for teams working with individuals with T1DE which would be valuable for not just diabetes teams, but also for eating disorder services who may have less knowledge of T1DE.

### **Reflective Commentary**

Within constructivist grounded theory, the researcher needs to be aware of their own beliefs and assumptions and how these shape the research they are conducting (Charmaz,

2014). Through the research process, I engaged with reflexivity by writing memos and journal notes. This helped me to become more aware of the privileges I held and helped me to understand further how these may shape the questions I was asking, as well as the analysis I was undertaking.

Whilst I had hoped that the teaching I received and a previous placement in a diabetes service would have equipped me with an expert understanding of the issues, I soon realised there were many aspects to living with type 1 diabetes that I had not even begun to consider because of the privileges I held with my physical health. To position myself, I am a white trainee clinical psychologist in my 30s with no physical health conditions. The process of constant comparisons and memo writing that were part of utilising a grounded theory approach helped me to identify some of the issues that may have otherwise gone undetected.

For example, when participants spoke about the pain they experienced during recovery, I initially made an assumption, during one of the first interviews that they were referring to the pain they experienced when injecting insulin. Making a memo of this helped bring this to my attention and then I became aware of when this was mentioned in a subsequent interview and was able to note how it was spoke about in a different way. Conversations with my research supervisor and reflecting on the notes I made, allowed me to become more aware to differences in pain and complications between participants that I was previously not aware of. If I had not investigated the concept of pain more fully and had assumed it was just the general pain of injecting that everyone gets with type 1 diabetes, I may have missed out on a fundamental link within the recovery process. This overall process of constant comparison and reflection therefore helped identify things that I might have missed due to my own privilege with my health.

The overall research process has made me reflect on my clinical work and the value of questioning the stance and assumptions that I may hold about something or someone when in a therapy room. I hope to take this information with me in my clinical work and to constantly remind myself of the experts in the room and where my blind spots might be due to the privileges that I hold.

In addition to this, I leave this chapter with a newfound appreciation for research and how powerful it can be in giving people a voice. Throughout my career, I have been open to feedback from service users about my clinical work, knowing that the opinion of those with lived experience is greatly valued. However, when conducting this research, it really highlighted to me not only how powerful this voice is, but also the importance of it being heard. It was evident in the interviews conducted that the type 1 community is passionate about diabetes care, but sometimes, they can feel misrepresented or powerless within certain settings. I was really struck by how grateful many of the participants were at the end of the interview for doing research in this area and how helpful they reported it was to reflect on their journey of recovery. I hope I have been able to give their stories justice.

Lastly, I'd like to share a deeper and more personal reflection on the research process. It has been a challenging year, and whilst trying to conduct this thesis, I experienced some significant life changes which had a notable impact on my mental health and, thus, my ability to concentrate. I attempted to 'push through' in hopes that I could make the deadlines that I had set myself despite the emotional impact of the things I was being tested with.

I soon realised the ticking clock and looming deadline and experienced a sense of panic regarding how I was going to give the stories I had heard justice in such a short space of time. I struggled with the idea of rushing this process just to 'get through it' as this did not sit well with my values, and yet I still felt I 'should' continue. When I stepped back and

reflected on what was keeping me from hitting the pause button, I soon realised that shame and stigma were underpinning my decision not to ask for additional time. I was worried about how others would see my decision to ask for additional time off. I felt fearful of the stigma that was associated with 'being off sick' as well as experiencing mental health difficulties.

Coming back into the research process after a small amount of time away, I realised how improved my concentration and functioning were compared to where they were before. I now have a better understanding of how quickly shame can infect and drive decisions that take you away from your values. I hope that throughout my career, I can remind myself of the lessons I have learned regarding boundaries and the importance of self-compassion. I am pleased to say that I have finished this research in line with my values, and I hope this research can go some way in helping someone as it inadvertently did for me.

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## Word Count

### Chapter 1

Abstract and Keywords	187
Main Text (Excluding tables, figures, and references)	4,768
Tables, figures, and references	3,879
Appendices	2,508

### Chapter 2

Abstract & Keywords	200
Main Text (Excluding tables, figures, and references)	7,793
Tables, figures, and references	794
Appendices	8,105

### Chapter 3

Main Text (Excluding tables, figures, references)	4,091
Tables, figures, references	617

### Miscellaneous

Title pages, declaration, thesis abstract, acknowledgement, and contents	1504
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Total Main Text : 16,652

Total including title pages, tables, figures, and references: 34,464