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# **Type 1 diabetes and disordered eating: Parliamentary Inquiry**

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**Sir George Howarth MP and  
the Rt. Hon. Theresa May MP**

**Published 23rd January 2024**

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*“The issue of T1DE is simply too expensive to ignore, for example, having a single patient on dialysis as a result of kidney failure from their T1DE costs £30k a year.. Money is wasted by the NHS in treating people with T1DE ineffectively or not treating them at all.”*

Dr Jaqueline Allan, Founder of DWED,  
Diabetics with Eating Disorders

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## Foreword

**T1DE – type 1 diabetes and disordered eating – is not an acronym known to many, but to those who suffer from T1DE it can be a life sentence. Imagine you are a young person whose concern about their body image leads them to an unhealthy relationship with food. You are encouraged to eat several times a day. Then imagine that you also have type 1 diabetes and must inject insulin every time you eat, knowing that insulin can lead to you putting on weight. Finally imagine that the support you receive from the NHS treats each condition separately and no one seems able to treat you as a whole person, understanding your conflicting needs.**

This is the situation in which too many people with type 1 diabetes find themselves. Sadly, it can lead to complications such as kidney problems, amputations and blindness. It can also lead to death.

It was a sense that this was an issue that was not being addressed properly that led us to set up this inquiry. As we took evidence, it became clear not only that this was indeed a problem in the UK, but that it was also a condition that was not receiving enough attention internationally.

We are grateful to all those who gave evidence, particularly those who themselves suffer from T1DE whose first-hand experience was invaluable to hear. We are also grateful to JDRF – the leading charity for type 1 diabetes – for providing the secretarial support for this inquiry.

We also thank those in the NHS who have been working to treat and support those with T1DE and to draw greater attention to the issue.

This report describes the problem, identifies the issues that arose from our evidence sessions and sets out a number of recommendations for the NHS. We urge the Government and NHS England not just to consider these recommendations but to implement them. While there might be concern about the initial cost, a different approach to T1DE would not only improve the lives of many people with type 1 diabetes, but could also in the longer term save the NHS and the Government money, by reducing the number of complications that arise and hence reduce the pressure on the NHS and other government budgets.

T1DE has been ignored by too many for too long. The time has come to act.

**The Rt. Hon. Theresa May MP and Sir George Howarth MP**

## 1.0 Executive Summary

*“Many of the people treating Megan hadn’t even heard of T1DE/Diabulimia, so we could understand why the thought of going back to a place where even basic type 1 care was a challenge absolutely terrified her. Megan left us a letter explaining that she felt there was no place of safety and understanding available to her, and she didn’t have the energy left to continue to battle with a system that had nowhere for her to go.”*

Lesley and Neal Davison, parents of Megan Davison who took her own life aged 27 as a result of T1DE

The parliamentary inquiry into eating disorders in type 1 diabetes aimed to gather evidence from experts, those with direct lived experience, both professional and personal, and to hear from those working in the charity sector.

The report aims to put a spotlight on and provide scrutiny of the current funding and provision of T1DE services in the UK. Its purpose is to help prevent T1DE and support those living with T1DE to recover and live well with type 1 diabetes. This is the first parliamentary inquiry of its kind, to establish prevention, treatment, care, and cure in the field of T1DE. The findings are uncompromising in the way that people living with T1DE have been let down due to the lack of research and integration of health services.

We are grateful that so many came forward to give evidence to the inquiry and are also grateful to those who have worked with patients, conducted research, and provided heartfelt lived experience testimony. The 38 witnesses from a range of backgrounds and expertise have been central to identifying the report’s findings and recommendations. Five evidence sessions took place to identify evidence-led recommendations to ensure the NHS and research infrastructure are best equipped to tackle the complexities affecting this at-risk group. The inquiry is an important step in raising policy makers’ understanding of the condition, raising awareness, identifying causes, and helping identify those who might be struggling.

Type 1 diabetes is a chronic autoimmune condition, the effect of which results in the pancreas being unable to produce insulin – the hormone required to absorb glucose. T1DE, or type 1 diabetes with disordered eating, is a life-threatening eating disorder specific to people with type 1 diabetes. It involves disordered eating behaviours such as restricting insulin to control weight or body image. Prevalence studies are limited, but it appears to affect as many as 144,000 of the 400,000 people in the UK with type 1 diabetes.

Risk factors include a history of disordered eating, diabetes-related stress, fear of hypoglycaemia and poor body image. Symptoms include blood sugar manipulation, unstable blood glucose levels, obsessive thoughts and weight changes. Complications can include diabetic ketoacidosis, chronic hyperglycaemia, malnutrition, neuropathy, sight loss, increased risk of mental health disorders and other eating disorders. Without appropriate treatment, patients can and do currently die from T1DE. This inquiry and subsequent report highlight 9 key findings and twelve recommendations regarding the prevention and treatment of T1DE. A key issue is the absence of internationally

recognised diagnosis criteria for T1DE, which hampers accurate diagnosis and classification of the condition. Recommendations also suggest that the existing guidelines by the National Institute for Health and Care Excellence (NICE) need updating to reflect the specific needs of people with T1DE. Furthermore, there is an emphasis on the importance of establishing an approved treatment and care pathway that integrates various healthcare disciplines to address the complex nature of T1DE. The report underscores the highly stigmatised nature of the condition and the need for increased information, awareness, and support for people with T1DE. Insufficient training for healthcare practitioners in recognising and managing T1DE is also identified as a concern.

Additionally, the report highlights the lack of structured and funded prevention strategies for T1DE, despite the high medical risk to those who develop T1DE. As part of the inquiry, it was repeatedly raised that it is reasonable to assume that the NHS identifies only the most severe cases of T1DE, typically following hospitalisation due to severe complications. These patients are frequently of normal weight, and even though their risk of mortality is 30 times that of age-matched controls<sup>1</sup>, they are frequently not prioritised by under-resourced eating disorder (ED) services that must limit access due to high demand and capacity constraints.

The report specifically notes the lack of integration between the different aspects of diabetes and eating disorder specialisms, both within the service approaches and the collection and sharing of data. This incongruence poses a risk to the successful treatment and management of T1DE patients. Addressing these issues requires the development of a standardised T1DE pathway, common frameworks, and improved technical infrastructure to ensure secure, ethical, and efficient data sharing across all specialisms within the NHS. Good practice is identified, particularly the role of NHS England pilots. However, it should be noted that whilst NHS England's National Diabetes Programme can fund pilots, permanent costs for running services after the completion of the pilot then become the responsibility of local commissioning boards. There is concern that local commissioners will judge the relative costs of integrated T1DE service provision to be too high to fund, given the relatively small local population of T1DE requiring such service. In addition, this report acknowledges the limited research conducted on T1DE relative to the scale of its complexity, suggesting a need for further investigation and understanding.

Recommendations focus on securing an international diagnosis consensus, establishing the health economic value of multidisciplinary teams to treat T1DE and the options to understand scale among other issues. While the Royal College of Psychiatrists (RCPSYCH) issued guidance as recently as May 2022 on recognising and managing medical emergencies in eating disorders specifically tailored to type 1 diabetes<sup>2</sup>, there remains no consensus on how best to define this condition. The lack of a clinical definition, the inquiry heard, is particularly hampered by the lack of opportunities people with the condition have to share their experiences and co-produce clinical interventions.

In summary, the report emphasises the urgent need for improved recognition, diagnosis criteria, guidelines, treatment pathways, support, training, prevention initiatives, and research in order to effectively address the challenges associated with T1DE.

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<sup>1</sup> Guidance on Recognising and Managing Medical Emergencies in Eating Disorders; Royal College of Psychiatrists, May 2022, p4

<sup>2</sup> Guidance on Recognising and Managing Medical Emergencies in Eating Disorders; Royal College of Psychiatrists, May 2022 [https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr233---annexe-3.pdf?sfvrsn=c45bd860\\_14](https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr233---annexe-3.pdf?sfvrsn=c45bd860_14)

## 2.0 Background

### 2.1 Purpose of the inquiry

The parliamentary inquiry into eating disorders in type 1 diabetes, was launched in June 2022 by Sir George Howarth MP and The Rt. Hon. Theresa May MP, and supported by JDRF (as the secretariat). It gathered evidence from experts: those with direct lived experience, clinical leaders, researchers and voluntary sector leaders.

The inquiry aims to put both a spotlight on and scrutinise the current funding and provision of T1DE services in the UK, with the aim of helping to prevent T1DE and support those living with T1DE to recover and live well with type 1 diabetes.

T1DE can be life threatening. It is misunderstood and lacks clinical recognition, which can result in inadequate support and limited access to specialised care. The T1DE inquiry seeks to raise awareness about the prevalence and impact of disordered eating in people with type 1 diabetes, identify the underlying causes and contributing factors, and propose strategies to improve early detection, prevention, and treatment. By addressing the specific challenges faced by those with T1DE, the inquiry aims to improve the overall health outcomes and quality of life for people living with type 1 diabetes and disordered eating.

This report intends to create evidence-led recommendations to ensure the NHS and research infrastructure are best equipped to tackle the complexities affecting this at-risk group.

### 2.2 What are type 1 diabetes and T1DE?

Type 1 diabetes, also known as insulin-dependent diabetes, is a chronic autoimmune condition in which the body's immune system mistakenly attacks and destroys the insulin-producing cells in the pancreas. As a result, people with type 1 diabetes are unable to produce sufficient insulin, the hormone responsible for regulating blood glucose levels. The condition can develop at any age. Type 1 diabetes requires lifelong insulin therapy to manage blood glucose levels and prevent complications. Its prevalence varies worldwide, with estimates suggesting that approximately 400,000 people are currently living with type 1 in the UK<sup>3</sup>.

Type 1 and disordered eating, known as T1DE, is an eating disorder in a person with type 1 diabetes. People with T1DE may develop disordered eating behaviours or restrict the amount of insulin they take on purpose, as a psychological consequence of distress and burnout or to lose weight. They may also experience bulimia or anorexia alongside their type 1 diabetes.

T1DE can have life threatening consequences for both physical and mental health, including unstable blood sugar levels, diabetic ketoacidosis, malnutrition, and an increased risk of developing other mental health disorders, such as depression and anxiety.

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<sup>3</sup> JDRF Type 1 diabetes facts and figures, <https://jdrf.org.uk/information-support/about-type-1-diabetes/facts-and-figures/>



*"I was diagnosed with type 1 diabetes at the age of three in 1990 and have had no psychological support in those 32 years. The expectation of how I was supposed to control my diabetes was so high from other people it was unachievable and unrealistic. I couldn't reach perfect, so the only thing I felt I could achieve was being uncontrolled, so I developed an eating disorder and that became a coping mechanism. My first signs of T1DE were in year eight of secondary school, where I started omitting insulin, and things got worse after leaving paediatric care, as I struggled with bulimia as many as four times a day. I would hide how I felt but underneath my smile I hated myself, my body and the stress that my type 1 diabetes caused my loved ones. By omitting insulin, I could numb the relentless burnout that managing type 1 diabetes brought. I could also eat any food I wanted, and without taking insulin, I would lose instead of gain weight."*

Sara, on living with type 1 diabetes and T1DE

There is limited research available on the prevalence of type 1 diabetes with disordered eating (T1DE), but some studies suggest that it may affect a significant proportion of people with type 1 diabetes. Evidence suggests that occurrence is more common in women than in men. Disordered eating behaviours are reported in up to 40% of females and up to 15% of males with type 1 diabetes<sup>4</sup>.

Additionally, people with type 1 diabetes are at increased risk of developing additional eating disorders, such as anorexia nervosa, bulimia nervosa, and binge eating disorder, compared to the general population<sup>5</sup>.

Recent studies have reported a substantial rise in the number of adolescents with eating disorders. It is thought that this is driven by social isolation and social media influences. Furthermore, it is well-established that people who suffer from eating disorders experience reduced life quality and are at a risk of increased mortality<sup>6</sup>.

The development of T1DE can be influenced by a number of factors, including both genetic and environmental factors. As with all eating disorders, T1DE does not have one single cause, but some potential risk factors for T1DE may include:

- A history of disordered eating or body image concerns: people with a history of disordered eating, dieting, or body image concerns may be more likely to develop disordered eating behaviours in the context of type 1 diabetes.
- Diabetes-related stress: The stress associated with managing diabetes, including frequent blood glucose monitoring and insulin injections, may increase the risk of developing disordered eating behaviours.
- Fear of hypoglycaemia: The fear of hypoglycaemia, or low blood sugar, may lead some people with type 1 diabetes to intentionally skip insulin doses or manipulate their blood sugar levels in an attempt to avoid hypoglycaemic episodes.

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<sup>4</sup> Hanlan ME, Griffith J, Patel N, Jaser SS (2013) Eating disorders and disordered eating in type 1 diabetes: Prevalence, screening, and treatment options. *Curr Diab Rep* 13: 909-16

<sup>5</sup> Trafford AM, Carr MJ, Ashcroft DM, Chew-Graham CA, Cockcroft E, Cybulski L, Garavini E, Garg S, Kabir T, Kapur N, Temple RK, Webb RT, Mok PLH. Temporal trends in eating disorder and self-harm incidence rates among adolescents and young adults in the UK in the 2 years since onset of the COVID-19 pandemic: a population-based study. *Lancet Child Adolesc Health*. 2023 Aug;7(8):544-554

<sup>6</sup> van Hoeken D, Hoek HW. Review of the burden of eating disorders: mortality, disability, costs, quality of life, and family burden. *Curr Opin Psychiatry*. 2020 Nov;33(6):521-527

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- Poor body image or self-esteem: Negative body image or low self-esteem may contribute to disordered eating behaviours as people with type 1 diabetes may attempt to control their weight or appearance through manipulation of their diabetes management.

T1DE poses a particular risk for people living with type 1 diabetes due to the condition and food being intrinsically linked. The importance to people living with type 1 diabetes to monitor, consider and then interpret consistently and relentlessly their food intake poses significant risks to those susceptible to developing an eating disorder. People with T1DE can present a complex relationship with food and dieting, which can develop into an eating disorder and, consequently, particularly adverse health outcomes.

Many necessary actions are required of people with type 1 diabetes, including the need to eat to treat hypoglycaemia, the need to estimate carbohydrates in food portions, the need to monitor glucose levels and dose with insulin. These actions can create stress and burden, which in some people can progress into eating disorders.

As stated in a July 2019 issue of the *Journal of Eating Disorders*, *'adolescence is a time of increased risk for both eating disorders and for worsening of glycaemic control. The latter could reflect metabolic changes during this time, and as well it is the period when responsibility for insulin administration transitions from the parent(s) to the child.'*<sup>7</sup>

Dr Sophie Coleman, a senior lecturer at the School of Psychology at the University of Central Lancashire reported to the inquiry that her research identified common themes that people with T1DE reported in relation to their reasons for restricting insulin.

These included: fear of weight gain, they were finding it hard to cope with their type 1, they felt different from their peers, they felt like they had a lack of control over their lives, they restricted insulin as a form of self-harm.

Some of the symptoms of T1DE may include intentional manipulation of blood sugar levels, such as skipping insulin doses or overusing insulin to induce hyperglycaemia or hypoglycaemia; unstable blood sugar levels, with frequent episodes of hyperglycaemia or hypoglycaemia; obsessive thoughts or behaviours related to food or diabetes management; anxiety or depression related to diabetes management or disordered eating behaviours; and unexplained weight loss or weight gain.

T1DE can have severe psychological and life-threatening physical consequences. Psychological effects include social withdrawal and conflict with friends or family compounded by feelings of low self-worth and shame. It is common for people with T1DE additionally to experience conditions such as depression, anxiety, and diabetes distress.

The inquiry heard from many witnesses who had experienced T1DE that they often felt blamed by Health Care Professionals (HCPs) when unable to maintain a healthy regime.

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<sup>7</sup> Goebel-Fabbri, A., Copeland, P., Touyz, S. et al. EDITORIAL: Eating disorders in diabetes: Discussion on issues relevant to type 1 diabetes and an overview of the Journal's special issue. *J Eat Disord* 7, 27 (2019)

The physical complications that can arise from T1DE can be deadly. This includes diabetic ketoacidosis (DKA), a life-threatening complication that occurs when the body does not have enough access to insulin, consequently blood glucose levels become too high, turning the blood acidic. This can cause coma and death if not treated swiftly.

Over time, chronically high glucose levels, can lead to long-term complications such as neuropathy, retinopathy, and cardiovascular disease; malnutrition and other nutritional deficiencies due to manipulation of food intake or insulin doses.

Studies have also highlighted that those who restricted their insulin had a mortality rate over three times higher than those who did not. Age of death amongst those who restricted their insulin intake was noticeably lower, an average of 45 years opposed to 58 years for those not restricting their insulin intake<sup>8</sup>. Furthermore, evidence demonstrated that the frequency of insulin restriction also impacted on the likelihood of mortality.

### 2.3 Lack of UK and international consensus on T1DE diagnosis

T1DE is not listed as a formal medical diagnosis<sup>9</sup>. Despite this, as highlighted previously, in 2022 the Royal College of Psychiatrists (RCPSYCH) published “Guidance on Recognising and Managing Medical Emergencies in Eating Disorders: type 1 diabetes and eating disorders (T1DE)”. While this provides diagnostic criteria, it acknowledges that there is no consensus on how best to define this patient group<sup>10</sup>. One aim of the inquiry is to influence the momentum for an international agreement so that this at-risk group can be identified, recognised and treated appropriately. The publication from the RCPSYCH is a new step for T1DE. It will have a significant effect in identifying a patient cohort who could and should be eligible for treatment.

The RCPSYCH is not the only institution acknowledging this overlap between type 1 diabetes and eating disorders. The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care in England and Wales, such as guidance on treatment pathways, medicines, and medical technology.

The NICE Guideline NG17 on type 1 diabetes in adults recommends to diabetes teams that members of professional teams should be alert to the possibility of bulimia nervosa, anorexia nervosa and disordered eating in adults living with type 1 diabetes.<sup>11</sup>

The NICE Guideline NG18 (diabetes in children and young people) also highlights this issue. It recommends that healthcare professionals (HCPs) should be aware that children and young people with type 1 diabetes have an increased risk of eating disorders. NICE calls for children and young people who present both conditions to be offered joint management with diabetes and mental health teams<sup>12</sup>. However, both NG17 and NG18 fall short of recommending an integrated care pathway.

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<sup>8</sup> Goebel-Fabbri AE, Fikkan J, Franko DL, Pearson K, Anderson BJ, Weinger K (2008) Insulin restriction and associated morbidity and mortality in women with type 1 diabetes. *Diabetes Care* 31(3): 415-419

<sup>9</sup> Diagnostic And Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR)

<sup>10</sup> Guidance on Recognising and Managing Medical Emergencies in Eating Disorders; Royal College of Psychiatrists, May 2022, p4

<sup>11</sup> NICE guideline NG17: Type 1 diabetes in adults: diagnosis and management p.45

<sup>12</sup> NICE guideline NG18: Diabetes (type 1 and type 2) in children and young people: diagnosis and management p.27

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The NICE Guideline Eating Disorders: recognition and treatment (NG69) makes specific recommendations for people living with diabetes and an eating disorder stating that ‘there is limited evidence and randomised controlled trials are needed’ ... for ... ‘people with an eating disorder and the same comorbidity (such as type 1 diabetes)’.<sup>13</sup>

Some progress is starting to be made. The RCPSYCH ‘Guidance on Recognising and Managing Medical Emergencies in Eating Disorders: type 1 diabetes and eating disorders (TIDE)’ is a good starting point. Furthermore, in 2022 NICE published new quality standards for diabetes recommending that children and young people are offered access to mental health professionals with an understanding of diabetes.

These are positive steps in the right direction. However, the NICE guidelines for diabetes do not go far enough.

*“While there is mention of eating disorders and type 1 diabetes, references are hidden and generic. What is needed is a full treatment and care pathway approved by NICE, alongside appropriate screening tools, training for health care practitioners, improved communication between health care specialisms and support for people at risk or living with TIDE outside of clinical settings including peer support.”*

Sarah Alicea, Clinical Lead Diabetes Dietitian, NHS England TIDE Pilot

### 2.4 Prevalence of TIDE among people living with type 1 diabetes

There is a lack of knowledge about the scale and incidence of TIDE due to the need for formal diagnostic criteria. Present studies show that approximately 400,000 people in the UK currently live with type 1 diabetes<sup>14</sup>. Studies of those living with type 1 diabetes have suggested that between 8% and 36% also experience some form of eating disorder both sub clinical and clinical, equalling as many as 144,000 in the UK alone<sup>15</sup>.

There are significant barriers to identifying the accurate scale and consequences of the condition. The inquiry heard from many lived experience witnesses who helped uncover some of the recurrent and isolated problems and issues faced by those living with TIDE. There appears to be limited joined up working and practice between clinical teams of different forms outside of the current pilot areas, leading to patients being passed from one team to another. Another difficulty in assessing the scale lies with some healthcare practitioners appearing unconfident in providing appropriate referrals to eating disorder services. This in part stems from the eating disorder treatment criteria being untailored to TIDE characteristics.

There are several barriers to identifying the condition, with evidence suggesting it is a hidden problem lacking the serious attention it needs; however, resulting in a life-threatening illness for individuals and high cost in healthcare provision to the taxpayer.

### 2.5 Diabulimia

‘Diabulimia’ is not recognised as an official medical diagnosis but rather a term used to describe the specific behaviour of people with type 1 diabetes who omit insulin for

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<sup>13</sup> NICE guideline NG69: Eating disorders: recognition and treatment p.42

<sup>14</sup> Hex N, Bartlett C, Wright D, Taylor M, Varley D (2012) Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs. *Diabetes Medicine* 29(7): 855-862

<sup>15</sup> TIDE Parliamentary Committee Session witness: Marietta Stadler

weight loss. People with type 1 diabetes require insulin to regulate their blood glucose levels, as their body does not produce insulin on its own. However, some people with type 1 diabetes may reduce or skip insulin doses to lose weight or prevent weight gain. Type 1 diabetes with disordered eating poses significant dangers to both physical and mental health.

When people with type 1 diabetes engage in disordered eating behaviours, such as restricting insulin or manipulating blood glucose levels, it can lead to a dangerous imbalance in glucose levels. This can result in hyperglycaemia (high blood glucose) or hypoglycaemia (low blood glucose), both of which have severe and potentially deadly consequences. Prolonged hyperglycaemia increases the risk of long-term complications like cardiovascular disease, kidney damage, nerve damage, and eye problems. Repeated episodes of hypoglycaemia can cause seizures, loss of consciousness, or even life-threatening complications.

Moreover, disordered eating can disrupt the delicate balance of insulin and glucose regulation, making it challenging to achieve stable blood glucose control. Psychologically, people with type 1 diabetes and disordered eating may experience increased stress, anxiety, depression, and a distorted body image. The intricate interplay between diabetes management, food, and body image creates a complex and potentially life-threatening situation that necessitates comprehensive care and support from healthcare professionals who specialise in both diabetes and eating disorders<sup>16</sup>.

Given the relatively small research base into T1DE, there is little information that outlines the exact increased risk of death. One recent study, looking at adolescents and young adults with T1DE reported that risk of DKA was three times higher, with a sixfold increased risk of death when compared to those without eating disorder<sup>17</sup>.

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<sup>16</sup> Diabetes Type 1 with eating disorder: T1DE, National Centre for Eating Disorders, <https://eating-disorders.org.uk/information/diabulimia/>

<sup>17</sup> Gibbings NK, Kurdyak PA, Colton PA, Shah BR. Diabetic Ketoacidosis and Mortality in People With Type 1 Diabetes and Eating Disorders. *Diabetes Care*. 2021 Aug;44(8):1783-1787.

## 3.0 Findings (identification of the problems and best practice solutions)

### 3.1 Lack of UK and international consensus on diagnostic criteria

As previously indicated, T1DE is not listed as a formal medical diagnosis despite RCPSYCH publishing its 'Guidance on Recognising and Managing Medical Emergencies in Eating Disorders: type 1 diabetes and eating disorders (T1DE)'. This is acknowledged by RCPSYCH, with NICE stating that there exists little evidence on which treatments work best for people with an eating disorder and comorbidity<sup>18</sup>.

Professor Ingrid Willaing Tapager, who investigated T1DE programmes in Denmark to assess successes and implementation described treatment as being very limited. She told the inquiry:

*"Treatments were low, with only seven patients referred to psychiatric units, who were then later rejected for not fulfilling diagnostic criteria. There is a lack of consensus on T1DE and an urgent need for T1DE terminology. To do this, the development of an international network needs to take place. When asked, healthcare professionals suggest they avoid the subject of T1DE because they have no tools available to deal with the condition."*

Professor Ingrid Willaing Tapager, Head of Diabetes Management Research, Steno Diabetes Center, Copenhagen

Dr Jacqueline Allan, Founder of Diabetics with Eating Disorders and Trainee Clinical Psychologist told the inquiry:

*"While guidelines and the NICE guidelines regarding eating disorders and their sections on T1DE specifically are very important, guidelines remain only as good as the people who are going to follow them. RCPSYCH T1DE guidelines are completely new and could have a significant effect in increasing the numbers of people flagged in screening, diagnosed, and therefore going on to receive treatment."*

Dr Jacqueline Allan, Trainee Clinical Psychologist & DWED

Witnesses indicated that the lack of consensus and the only recently emerged RCPSYCH T1DE specific guidelines mean there is work to be done to educate and apply the guidelines in their entirety. It was suggested that this must be met with further action on international cooperation, including in the form of research; as highlighted by NICE itself, insisting that research is limited and randomised controlled trials are needed.

### 3.2 Stigma around diabetes and eating disorders

*"The disordered eating mindset doesn't have to be there all along. Many people would never have developed an eating disorder if they hadn't had type 1 diabetes due to the special focus on food, weight, feelings of guilt and stigma: all drivers of an eating disorder. Additionally, comments from other people, misconceptions and stigma towards type 1 diabetes can take a toll on a person's mental health and potentially put them more*

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<sup>18</sup> Eating disorders: recognition and treatment, May 2017, National Institute for Health and Care Excellence, NICE. <https://www.nice.org.uk/guidance/NG69>

*at risk of developing T1DE. Interactions with a healthcare practitioner can be a possible contributor to a person developing T1DE, with it being an imperative that the patient encounters a positive interaction.”*

Dr Marietta Stadler, NIHR Clinical Scientist, Diabetes Consultant, King’s College London

Stigma is often a contributing factor in eating disorders and diabetes, posing a particular risk in T1DE patients. The inquiry received powerful, professional, and personal testimony from those currently or previously living with T1DE who explained the landscape regarding stigma.

Societal stigma can manifest in different ways, including through social media, advertising, or one’s peers. It is often driven by a lack of understanding or misinformation about type 1 diabetes, leading to misconceptions about the condition. Healthcare professionals can also contribute to the stigma surrounding type 1 diabetes, particularly when they lack adequate training and knowledge. This can lead to missed diagnoses or inadequate treatment, exacerbating the condition, and putting patients at risk.

*“I don’t want to add to the stigma. The stigma of being ‘fat, lazy’ and that we’ve done this to ourselves. I believe people would think differently had we been thin. The bullying I received occurred intermittently, with most instances being about weight. Unfortunately, while one or two teachers had awareness, there existed little support.”*

Amy, personal experience of type 1 diabetes

The inquiry was told of how social pressures, known to be a significant factor in disordered eating, can create extraordinary pressures on people with type 1 diabetes. Insulin omission can result in significant weight loss. For some people with type 1, a way of alleviating the pressures of body image and desired weight loss is to restrict insulin. Insulin omission can also result in a psychological feeling of emotional numbness. All these factors contribute to risk factors in the development of T1DE with severe and enduring physical and emotional ill health.

Another individual with T1DE, who provided oral evidence told the inquiry that she has always struggled with weight. Despite warning signs, this stigma existed among healthcare professionals she encountered, a risk indicated by Dr Stadler.

*“I was diagnosed at 19 with T1DE, having always struggled with weight. Despite trying every diet, I continued to struggle and remained afflicted with obesity. By the end of February 2020, I felt sick and left unable to cope any longer despite having a record of being a ‘good diabetic’. Despite my struggles, I was informed by my GP that my BMI meant I could not be considered as someone living with an eating disorder because it was ‘too high’. I was as a result, given no support for my illness. Sadly, some healthcare professionals continue to misdiagnose people like me who suffer from type 1 complications.”*

Kathryn, diagnosed with T1DE at 19

It is clear from the inquiry’s oral evidence sessions, and the lived experiences of those who contributed, that people with T1DE can encounter both professional and societal stigmas, which can increase pressure on the individual. Societal pressures come in the



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form of bullying, social media, and peer pressure around issues of weight and ‘thinness’, while healthcare professionals are perceived to be undertrained on the subject, causing a reliance on old and inaccurate measurements to determine whether someone needs eating disorder support or not. All present factors that can lead to patients to look inwards, blaming themselves for not ‘managing’ their type 1 diabetes well enough despite identifiable barriers in their way of doing so.

*“As an actor at the start of my career, I asked a director how I could get into the Royal Shakespeare Company. He told me go to the gym. There is so much peer pressure and cultural stigma to look good. I am an individual, I am male. I live with type 1 diabetes. We need more visibility to break down shame and stigma of who may be experiencing T1DE. T1DE does not discriminate across age, gender or race.”*

Lawrence, who has experienced T1DE

A witness who did not want to be identified spoke of their struggles with weight, emotional numbness, and feeling dismissed by healthcare professionals despite their obvious struggles with T1DE. They emphasised the need for greater awareness and connection between type 1 diabetes and poor mental health among healthcare professionals. They provided further evidence indicating the stigma HCPs can have due to lack of awareness or training:

*“I recall at 13 being weighed regularly and living with a feeling of emotional numbness. The media, too, played its part. The pictures I saw influenced me to want to be as thin as possible to fit in with prevailing social standards. It was this that led to me being referred to children and adolescent mental health services, where I was told I was too complicated to deal with and that specialist support was needed. It seemed to me that there was very little knowledge and even no connection between diabetes and poor mental health made.”*

*“Despite troubles utilising services, it was not until 2020 that I could access a T1DE service through a pilot scheme, from which I was discharged last year. Despite my mental health being impacted directly by my experience as someone with diabetes, my GP continues to be dismissive due to my weight, believing it to be too large for me to have an eating disorder.”*

A witness who did not wish to be identified

The evidence presented in the inquiry highlights the prevalence of stigma around T1DE, which can exacerbate the condition and put patients at risk. Action needs to be taken to address the negative and false expectations around weight pushed by society, as well as the wrong stigmas perpetuated by healthcare professionals. Tackling these stigmas is essential for the proper diagnosis, treatment, and management of T1DE.

### 3.3 Treatment requires greater integration and specialist care

*“Megan was admitted to a residential eating disorder unit, but this proved again just how unfit for purpose things were. Once more Megan was put in a position where control of her medication was taken away and given to those who had no understanding of type 1. She had to explain and argue for her specific needs and take responsibility for battling to ensure she could remain safe. The responses required for T1DE are not the same as those*



*for a non T1DE eating disorder so much of the regime imposed was counterproductive and frustrating. Megan used the ignorance she encountered to create the opportunity for a second suicide attempt which perversely led to her discharge from the unit."*

Lesley and Neal Davison, parents of Megan Davison

3.3.1 Siloed treatment models lead to devastating health consequences for patients and long term do not provide value for money.

A recurrent theme across witnesses throughout the inquiry is that services lack integration and funding, health care professionals lack training. Professor Agnes Ayton, Chair of Faculty of Eating Disorders of the Royal College of Psychiatrists told the inquiry that research has shown that people with diabetes and eating disorders do not respond to standard eating disorder treatment and have high dropout rates from psychological therapies. This suggests that people living with T1DE find the current standard treatment, which encourages patients to maintain moderate carbohydrate intake while receiving matched insulin treatment, ineffective in preventing further weight gain. After initiating insulin treatment, patients gain weight, which contributes to fear of further weight gain particularly in young women, with consequent disordered eating and insulin omissions, which can be highly dangerous.

Professor Ayton highlighted that patients are often exposed to conflicting messages from the two disciplines. Eating disorder specialists actively discourage restriction of any type of foods, and diabetic teams recommend calorie and carbohydrate counting, weight loss, and using low fat products. The lack of an integrated approach may explain poor response rates and disengagement, and inadvertently reinforces eating disorder psychopathology.

Dr Jacqueline Allan, Trainee Clinical Psychologist and founder of the support group Diabetics with Eating Disorders (DWED) reported people contacting the group with the consistent issues that patients with T1DE were being viewed by their healthcare practitioners as 'non-compliant' in that they were not following the care instructions of their teams. They were not taking their insulin, not to be difficult or because they didn't want to, they were doing it as a result of their eating disorder. There was no joined up working and practice between different clinical teams in a patient's care pathway – diabetes and mental health teams weren't collaborating and communicating with each other for the care of their patient.

*"I was told by my diabetes team to weigh my food; I was told by my eating disorder team not to weigh my food. I was attempting to recover from my eating disorder, but I could not count my carbohydrates as I was instructed to by my diabetes team without the eating disorder voice becoming stronger and more controlling. In the eating disorder inpatient unit the treatment was chaotic, and the staff team were kind but had no knowledge of insulin management. The model was built to treat patients with anorexia, not type 1 diabetes. Everyone had to eat three meals and three snacks a day. The food regime ran counter to treating type 1 diabetes and hypoglycaemia and insulin dosing."*

Naomy, who has personal experience of T1DE

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Current siloed NHS structures and information technology also have a role in preventing integrated treatment.

*“There needs to be attention given to common obstacles to joint working in the NHS. For example, mental health and physical health teams are often held in different NHS Trusts and therefore use different IT systems and therefore different sets of electronic patient notes that are inaccessible to each other, have different physical bases, policies and procedures.”*

Dr Lindsey Rouse, Clinical Psychologist, T1DE Wessex NHS ComPASSION pilot

A significant contributing factor to the challenges faced in addressing T1DE is the scarcity of mental health professionals within the NHS available to oversee the multitude of specialised services required for T1DE.

The shortage of mental health professionals capable of effectively managing the intricate interplay between diabetes management and disordered eating exacerbates the complexities of T1DE care. In this context, it is imperative that the recommendations for future workforce planning encompass strategies to augment the availability of mental health experts specifically trained to address T1DE, ensuring comprehensive and seamless care for those grappling with this condition.

Prioritising the recruitment, training, and retention of mental health professionals specialised in T1DE will be paramount in bridging this critical gap in the healthcare system.

3.3.2 There is a role for the media in amplifying trusted, clinically approved information to raise awareness and understanding of T1DE and where and how to seek help, to run alongside the work of healthcare practitioners in identifying risk factors, establishing early intervention clinical treatments and referring acute cases to specialist centres.

3.3.3 Fundamental to treatment and recovery is the quality of the relationship that people living with T1DE have with their health care professionals and this requires focus and co-ordination at the onset of a patient’s treatment for T1DE. Consultant in eating disorders, Dr Anthony Winston, Coventry and Warwickshire Partnership NHS Trust and one of the leaders of the T1DE regional pilots, told the inquiry that patients living with T1DE feel angry and dispossessed when they are referred for treatment. The lack of formal diagnostic criteria and NICE/SIGN (Scottish Intercollegiate Guidelines Network) approved treatment pathway means that patients often have not previously been provided with the information or support that they need, and they feel shame and stigma. The initial contact meeting with the T1DE team and patient therefore needs to be established with a positive, responsive relationship. Patients need to feel that they are understood and that they can put their trust in the team, given frequent negative prior experiences of treatment.

Treatment needs to be tailored to the individual:

*“Beliefs and attitudes and lived experience needs to be built into treatment. If diabetes is viewed as a tyranny, it may be harder to treat than if it is viewed as a misfortune or inconvenience.”*

Deanne Jade, Founder, National Centre for Eating Disorders UK

3.3.4 Research on treatment efficacy is building a significant evidence base around the value of family-based treatment, where parents and family members are involved in the care and treatment of the child or adolescent with T1DE. Issues of patient confidentiality are intrinsic to treatment. However, greater exploration of the role and knowledge of family units may help to support treatment in some, though not all, adults living with T1DE.

*“We were on the outside watching our daughter spiral out of control, desperately trying to share what we knew with the people responsible for her care but always with the response that client confidentiality meant no one could meet with us, talk to us or take information from us. We needed someone to listen when we said that all her behaviours were deteriorating.”*

Neal and Lesley Davison, parents of Megan Davison

### **3.4 Greater interdisciplinary training for T1DE required**

The inquiry heard at every evidence session that professionals lacked national guidance and training in how to treat T1DE. A study conducted in 2020, published in The British Journal of Diabetes found that:

*‘Healthcare professional confidence is low when it comes to recognising and supporting people with T1DE, but there is an interest in learning more.’*

3.4.1 A lack of consensus over nationally and internationally recognised diagnostic criteria for T1DE hampers health care practitioners in identifying T1DE in the first place. The inquiry found that NICE and SIGN guidelines in both eating disorders and diabetes need updating, to recognise T1DE and create a structured care pathway.

3.4.2 Currently, healthcare practitioners in primary, hospital and specialist diabetes and eating disorder units report being unconfident in treating T1DE. As a result, patients are referred back and forth between specialist units that are designed to treat either an eating disorder or type 1 diabetes, but not designed to treat T1DE.

*“The healthcare professionals were too scared to say anything because they knew my condition was complex, and they didn’t want to get the discussion wrong.”*

Lynsey, who has personal experience of T1DE

3.4.3 Professor Agnes Ayton, Chair of the Faculty of Eating Disorders at the Royal College of Psychiatrists, gave evidence saying that a fundamental problem is the artificial split between mind and body across all forms of medical education and allied healthcare professional training. Specialist diabetes teams are all too often trained solely on the physical aspects of diabetes, whereas mental health staff receive no structured training on diabetes and very little on eating disorders, apart from child psychiatrists. Improving training is critical for specialist diabetes teams, general practitioners and eating disorder teams across the age ranges. Such training should be introduced at undergraduate level, so that the next generation of healthcare professionals have a basic awareness of co-morbidities of the condition. Structured training would require support from the General Medical Council, and the Academy of Medical Royal Colleges, alongside individual Royal

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Colleges, such as the Royal College of Physicians, Emergency Medicine, Paediatrics and Child Health, Psychiatrists. The national rollout of such training would require a small investment but would significantly improve patient safety.

*"I felt as if I was losing my identity when I was an inpatient in an eating disorder clinic. I felt as the odd one out because I was eating, but it was the type 1 diabetes that caused the challenges, and yet the healthcare professionals didn't get it."*

Kelly, on being treated with TIDE as an inpatient in an eating disorder clinic

A recent survey of 13 NHS adult community services covering a population of 10 million found that only 54% were able to offer evidence-based treatment for all eating disorders, and only 23% have staff trained in diabetes and eating disorders<sup>19</sup>.

*"When some type 1 patients have been referred to an eating disorder unit, they have been told they don't have an eating disorder."*

Dr Helen Partridge, Consultant in Diabetes at University Hospitals Dorset, ComPASSION project lead

3.4.4 The inquiry learned that the specialist diabetes psychologist workforce lacks capacity to meet demand. Where there are specialist psychologists working in diabetes teams, health outcomes are improved and healthcare costs of DKA admissions are reduced<sup>20</sup>. The inquiry therefore recommends a targeted focus and increase in specialist psychological diabetes therapists to provide prevention services, early intervention services and to support acute and severe cases with a range of evidence-based treatments.

Dr Rose Stewart, Consultant Clinical Psychologist for the Betsi Cadwaladr University Health Board, North Wales, made a recommendation to the inquiry that resources and support be funded to 'psychologise the system'. This could help ensure that staff of whatever discipline including general practitioners, felt confident to explore psychological needs of patients with open questions, active listening to normalise, not minimise a patients psychological needs and to be confident in a treatment pathway in which to refer and signpost for further support.

Professor Khalida Ismail, Professor of Psychiatry and Medicine, King's College London provided the inquiry with a framework for training and professional development:

1. Target subgroups of mental health practitioners where the presentations of type 1 diabetes are greatest
2. Create improved liaison between diabetes services and eating disorders psychiatry
3. Create standardised training delivered at a national level. King's College London partners will be launching credited modules on diabetes focused cognitive behavioural therapy
4. Generate hubs of expertise in TIDE where mental health practitioners develop a critical mass of clinical and academic expertise

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<sup>19</sup> TIDE Parliamentary Committee 1st Session witness: Prof Agnes Ayeton

<sup>20</sup>Watson A, McConnell D, Coates V. Reducing unscheduled hospital care for adults with diabetes following a hypoglycaemic event: which community-based interventions are most effective? A systematic review. J Diabetes Metab Disord. 2021 Jun 10;20(1):1033-1050. doi: 10.1007/s40200-021-00817-z. PMID: 34131570; PMCID: PMC8192108.

5. Undergraduate training in nursing and medicine in T1DE
6. Upgrade standard NICE/SIGN guidelines using the guidance established in the Royal College of Psychiatrists Medical Emergencies in Eating Disorders

### 3.5 Integrated treatment, a new way forward: NHS England T1DE pilots

The inquiry heard evidence about emerging best clinical practice in the form of NHS England T1DE pilots. In an inquiry which spanned international evidence of research and practice into T1DE, the benefits of the NHS, however fragmented, were clear. As the NHS is funded via general taxation and National Insurance contributions, the NHS is able to scope and fund pilots. These T1DE pilots can capture clinically robust evidence and define best practice. The inquiry heard that NHS England is showing international leadership in responding and treating people with T1DE, with the preliminary results demonstrating positive health outcomes.<sup>21</sup>

The first nationally funded T1DE pilot services in England became operational in 2019, located in London and the South of England. The sites developed an integrated diabetes and mental health pathway with an emphasis on personalised care and support and drew patients from a broad regional basis.

An independent mixed methods evaluation of the sites was commissioned to provide an overview of the different pathways and lessons learned from rollout. The evaluation partner was also commissioned to gather evidence on the impact T1DE services had on patient outcomes, staff experience and to provide analysis of NHS costs and savings to run the service.

The key headline findings from the independent evaluation were:

- The mean estimated change in HbA1c was a reduction of 2.3% (South West Coast service) and a reduction of 2.5% (London service).
- London Secondary Uses Services data showed a reduction in diabetes ketoacidosis patient admissions in the first year after entering the service compared to the previous year.
- The mean follow-up scores on psychological and quality of life measures suggested improvements in almost all areas.

The National Diabetes Programme Board reviewed the findings of the evaluation at the February 2022 Programme Board and supported the continuation of the existing sites, with the expectation that the pilots would work towards being sustainable through ICB commissioning by the 2023/24 financial year. The Programme Board also approved the expansion of T1DE services to other parts of England and approved funding to expand the service.

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<sup>21</sup> Partridge H, Figueiredo C, Rouse L, Cross, C, et al. (2020) Type 1 diabetes and disordered eating (T1DE): the ComPASSION Project - Wessex, *Practical Diabetes*: 37(4) p127-132.

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3.5.1 From April 2022, two years' funding was made available for up to five more T1DE sites across England. Using criteria that considered alignment with the minimum service specification required for T1DE services, the five sites selected by the National Programme Team include:

<b>Region:</b>	<b>Integrated Care Board:</b>
<b>Midlands</b>	<b>Coventry and Warwickshire</b>
<b>Midlands</b>	<b>Leicester, Leicestershire and Rutland</b>
<b>East of England</b>	<b>Norfolk and Waveney</b>
<b>North West</b>	<b>Cheshire and Merseyside</b>
<b>North East and Yorkshire</b>	<b>Humber and North Yorkshire</b>

Following the rollout of these additional pilot sites, there is an increased capacity in T1DE services, although there is not currently countrywide cover or access.

3.5.2 In parallel to service expansion and delivery, NHS England is progressing with work to commission an external mixed method evaluation of the existing and newly launched T1DE services, alongside an in-house quantitative study based on data obtained from the sites to further evaluate this pathway of care and inform future policy.

NHS England conducted a comprehensive cost-benefit analysis of the initiated pilots, contingent upon the understanding that ICSs (Integrated Care Systems) would sustain funding if the pilots proved successful. The evaluation undertaken by NHS England unequivocally demonstrated the success of these pilots in addressing the multifaceted challenges posed by T1DE.

As these pilots have yielded positive outcomes, it is incumbent upon the Integrated Care Systems to honour their commitment and ensure the continued allocation of resources. The effective outcomes of these pilots underscore the necessity for ICSs to be held accountable for their obligation to uphold the sustainable funding of initiatives that exhibit such promise in advancing the wellbeing of people living with T1DE.

*"I've had T1DE since I was 15 and I have had multiple episodes of DKA but didn't tell anyone about the eating disorder until 2020. Luckily, I was referred to a specialist T1DE team pilot. I had both a psychiatrist and diabetes team who supported me in a co-ordinated way. I felt validated because the teams assured me that there were others like me and stories like mine. I've received talking therapy such as CBT (Cognitive Behavioural Therapy) and support from my family.*

*"I have started to feel on the other side. In order to recover, a person with T1DE will experience extended periods of being uncomfortable physically with insulin and feeling emotionally numb. I found that the T1DE team would help with these feelings to help push through those of insulin and weight gain. It's so important that in areas which don't have a T1DE pilot that eating disorder units are trained in the understanding and treatment of T1DE."*

Ellie, living with T1DE on receiving treatment from an integrated T1DE pilot

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### 3.6 People living with T1DE need more support, information and awareness

3.6.1 The inquiry heard that people with T1DE felt misunderstood and isolated because there was not a common understanding of what T1DE is, even for people living with type 1 diabetes.

For patients and their families, knowing that T1DE is a recognised condition is an important first step to engaging with health care professionals in order to be able to recover.

In 2022, the eating disorder charity, Beat recorded 700 enquiries to their helpline about T1DE and questions about whether callers or their loved ones would classify as living with T1DE and would qualify for treatment. There was a particular spike of enquiries when ITV's Coronation Street ran a storyline where one of the central characters experienced T1DE, showing that more awareness and structured information is required from clinical and charitable sources. BEAT<sup>22</sup>, JDRF UK<sup>23</sup> and Diabetes UK<sup>24</sup> provide clinically approved sources of information.

There is a growing range of valuable information produced from the perspective of those who have lived with T1DE:

*"I was willing to talk about my experience of T1DE because both type 1 diabetes and eating disorders have shame and misunderstanding around them that harms those who live with them and prevents them from reaching out for support. I wanted to help other people who were struggling. The NHSE T1DE pilot team in Bournemouth supported the podcast as a form of information, helping me set it up and find speakers. My podcast has been listened to over 500 times and one person I know reached out to the T1DE Bournemouth team as a result of the podcast and is now receiving the treatment they need."*

Ariella, author and broadcaster of the T1DE Podcast

3.6.2 The role that peer support can play in treatment and recovery was repeatedly recommended.

Dr Carla Figueiredo, Consultant Psychiatrist for NHS England T1DE ComPASSION Project in Bournemouth told the inquiry that patients recovering from T1DE can join a peer support group on leaving the pilot treatment. More broadly, NHS England's National Diabetes Programme is embedding the principle that peer support is a central component for the treatment of type 1 diabetes with the ambition that in future peer support will be a funded clinical treatment pathway<sup>25</sup>. This will be a step forward.

*"Peer support has been a massive benefit to me, because it has helped me feel less alone and also it can help avoid the need to necessarily talk to family, which often can feel emotionally charged."*

Ellie, living with T1DE

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<sup>22</sup> Learn about eating disorders - BEAT (<https://www.beateatingdisorders.org.uk/>)

<sup>23</sup> JDRF - (<https://jdrf.org.uk/>)

<sup>24</sup> Diabetes UK (<https://www.diabetes.org.uk/>)

<sup>25</sup> The six principles of good peer support for people living with Type 1 diabetes - NHS England (<https://www.england.nhs.uk/long-read/the-six-principles-of-good-peer-support-for-people-living-with-type-1-diabetes/>)



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For those witnesses with lived experience, the inquiry was for many, the first time that they had been able to meet others with T1DE in person. Most had hunted through internet forums and blogs to find and connect with others. It was acknowledged that this pro-activity to find and connect with others takes confidence and mental resource. The support group Diabetics with Eating Disorders (DWED) had been a funded registered charity that closed a number of years ago. A Facebook forum continues<sup>26</sup>. In the USA the Diabulimia Helpline provides support for people with T1DE and also now provides structured education and training for healthcare practitioners across the USA to provide insight into lived experience as clinical practice evolves and improves<sup>27</sup>.

The inquiry heard that more structured support could be embedded in the form of a type 1 diabetes advocate or youth worker. David Hopkins, Diabetes Consultant at King's College Hospital T1DE Service explained how the pilot takes referrals from across London, integrating a range of diabetes, eating disorder and psychological therapies. He highlighted that all employed staff are medical professionals and therefore an area to explore in T1DE and diabetes care in general would be integrating care with a non-medical professional. A youth worker or a type 1 diabetes advocate may well be able to engage with a patient in a more personal way. This inquiry therefore recommends the availability of in-person and online moderated peer support so that people with T1DE can connect, grow in knowledge and confidence, learn and support each other to recover from a condition which is highly misunderstood, stigmatised and isolating.

*"I found support through peers and especially on discovery of a blog which encouraged me to reach out to the author. I then started talking to the eating disorder charity Beat, and the eating disorder community. I found podcasts and I learnt more about the NICE guidelines, and more from the eating disorder community. I then reached out to Beat, and I subsequently got referred to Bournemouth ComPASSION pilot. All this I have done off my own back, finding and being supported by others living with T1DE."*

Kathryn, living with T1DE

### 3.6.3 Transition from paediatric to adult services requires greater focus.

Half of people diagnosed with type 1 diabetes are diagnosed in childhood<sup>28</sup>. Those giving witness statements to the inquiry reported paediatric care appeared better funded than adult diabetes care with more consistency in named healthcare practitioners, ensuring more tailored treatments and improved person-centred care.

*"As someone who has experienced paediatric and adult care, I have a unique insight into the process someone like me may encounter. While in paediatric care, I knew the staff well and regularly came into contact with the same people or an informed replacement during appointments. My experience with adult services was markedly different, with me seeing another person every time with no record of what insulin I was on."*

Lyndsey, living with T1DE

Sara Crowley, Diabetes Transitional Care National Co-ordinator at NHS Wales, reported to the inquiry that paediatric and adult diabetes services do not always work in an

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<sup>26</sup>Online Support - Diabetics with Eating Disorders (<http://dwed.org.uk/online-support>)

<sup>27</sup>Diabulimia Helpline (<http://www.diabulimiahelpline.org/>)

<sup>28</sup>Thomas NJ, Jones S, Weedon MN, Shields BM, Oram RA, Hattersley AT (2018) Frequency and phenotype of type 1 diabetes in the first six decades of life: a cross-sectional, genetically stratified survival analysis from UK Biobank. *Lancet Diabetes Endocrinology* 6(2): 122-129



integrated way together, often resulting in patients with type 1 diabetes becoming disengaged with their clinic. Late adolescence is a point of vulnerability and risk for young people living with type 1 diabetes. Their adolescent brain is still maturing until the age of 25. They are learning to be independent in their diabetes self-management, often moving away from home for the first time. Their care needs to be tailored to this particular point in their lives. Targeted clinical support, ideally with a consistent team will help young people transition to adulthood, reducing the current risk of young adults falling between the gaps of two services and disengaging with their healthcare. The inquiry heard that it was inappropriate for funding streams to change right at the point when young people are potentially at their most vulnerable.

#### 3.6.4 There is a greater need to reflect diversity across information and support for people with T1DE

The inquiry heard that T1DE could manifest as a condition at any age and affect boys and men as well as girls and women, even if currently referrals are in the majority in relation to female patients. This presentation could well change.

*“We are seeing an increase in risk factors, behaviours and body dysmorphia in teenage boys and young men. This could be due to a rise in the depiction of boys and men on social media. We are finding that boys and young men more generally want to be bigger aiming for lean and muscly body type. For boys and young men this isn’t necessarily about being thinner. We need to consider how we adjust models of treatment for boys and men with type 1 diabetes to tailor to their needs.”*

Sarah Jaser, Director Paediatric Psychology, Associate Professor of Paediatrics

It will also be important for information and support materials to reflect patients from a range of cultures and socioeconomic backgrounds to ensure that patients see themselves genuinely reflected in information and support.

### 3.7 Funding for T1DE service provision requires investment

Eating disorder services are currently under-resourced and patients with T1DE are not currently prioritised. Evidence given highlighted that integrated T1DE clinical services require sustainable funding.

Professor Agnes Ayton, Chair of the Faculty of Eating Disorders at the Royal College of Psychiatrists reported that eating disorder services, particularly for adults, are in crisis due to chronic underfunding. She cited workforce shortages across all professional groups in combination with rising demand, which has accelerated since the pandemic. Consequently, Professor Ayton reported that it is reasonable to assume that the NHS identifies only the most severe cases of T1DE typically following hospitalisation due to severe complications. These patients are frequently of normal weight, and even though their risk of mortality is 30 times that of an age-matched control<sup>29</sup>, they are frequently not prioritised by under-resourced eating disorder services that must limit access due to high demand and capacity constraints.

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<sup>29</sup>Guidance on Recognising and Managing Medical Emergencies in Eating Disorders; Royal College of Psychiatrists, May 2022, p4

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*“We talk of funding, £100,000 was thrown at Megan’s treatment, inpatient and outpatient, and yet the diagnosis, training and support meant that that funding was not utilised to treat T1DE.”*

Lesley and Neal Davison parents of Megan Davison

The inquiry heard how collaboration and integrated services were central to clinical service provision for T1DE. This requires investing resources in collaboration and training to strengthen the infrastructure and systems. Dr Marietta Stadler, National Institute of Health Research Clinician Scientist and Honorary Diabetes Consultant at King’s College London emphasised the importance of funding co-ordination, so that integrated teams have the structured time to bring their specialist expertise into each case and work through integrated treatment provision which may vary according to the individual’s needs. She highlighted the fact that more diabetes specialist nurses who are trained in therapeutic interventions are required, but that it is expensive to train staff as they require supervision from other more senior clinical staff to ensure professional training is delivered to a quality standard.

The inquiry heard concerns over the uncertainty of long-term funding for the NHS England regional T1DE pilots. While the NHS England National Diabetes Programme can fund pilots, permanent costs for running services after the completion of the pilot then become the responsibility of local commissioning boards. There is a risk that local commissioners will judge the relative costs of integrated T1DE service provision to be too high to fund, given the relatively small local population of T1DE requiring such service.

*“The issue of T1DE is simply too expensive to ignore, for example, having a single patient on dialysis as a result of kidney failure from their T1DE costs £30k a year. Diabetes UK have found that kidney problems had the third highest cost out of all diabetes-related complications at nearly £1,000,000,000. Money is wasted by the NHS in treating people with T1DE ineffectively or not treating them at all.”*

Dr Jaqueline Allan, Founder of DWED, Diabetics with Eating Disorders

### 3.8 Limited investment in research, research challenges and opportunities

3.8.1 The current NICE Guideline for eating disorders is explicit: ‘There exists little evidence on which treatments work best for people with an eating disorder and comorbidity’<sup>30</sup>. The inquiry found that a research base is slowly emerging but requires greater funding and infrastructure in the UK and internationally.

*“There are very few clinical trials on T1DE, though there exists experiential research about the value of clinical interventions. One difficulty is that type 1 diabetes varies person to person, so developing control groups is challenging. The first gap is in identifying who is at risk with an evidence-based risk factor. The second is an understanding of who responds well to which treatments where there exists no reliable data. Third, we don’t know the effects on the brain of various forms and severity of T1DE.”*

Dr Jeanette Söderberg, Director of European Research, JDRF International

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<sup>30</sup>NICE guideline NG69: Eating disorders: recognition and treatment p.42

Research provides the evidence base for treatments and best practice, helping define short and long-term health outcomes, best practice evaluation and cost benefit for healthcare commissioners. However limited research funding and resource is given to eating disorder research and TIDE.

*“Despite the fact that eating disorders account for 9% of those with a psychiatric disorder in the UK, only 1% of annual government mental health funding in the UK was allocated to eating disorder research between 2015 and 2019<sup>31</sup>. Large-scale research studies are difficult to carry out due to funding constraints.”*

Professor Agnes Ayton, Chair Eating Disorders Faculty, Royal College of Psychiatrists

While increasing focus is given to the mental as well as physical effects of type 1 diabetes, there is still considerable progress to be made in achieving greater funding and research focus in psychosocial outcomes and particularly in TIDE research.

3.8.2 The inquiry heard that national and international professional conferences in the field of both diabetes and also eating disorders should provide greater focus on the emerging research on TIDE and scope for international collaboration. In the field of diabetes, international conferences are heavily sponsored by industry partners, who have no commercial interests in conditions such as TIDE, therefore the opportunity to present, network and collaborate internationally is significantly limited.

Professor Ingrid Willaing Tapager provided the inquiry with insight into the current conference landscape and the issues of gaining benefit from them in respect of TIDE.

*“At the Psychosocial Aspects of Diabetes conference in Copenhagen, psychosocial aspects of diabetes were the primary focus, however a lot of conferences don’t give attention to TIDE.”*

Professor Ingrid Willaing Tapager, Head of Diabetes Management Research, Steno Diabetes Center, Copenhagen

Dr Ann Goebel-Fabbri explained that at the American Diabetes Association conference, she was able to speak to professionals in the eating disorders field, but these conversations were not in an integrative sense; with the issue being incidental to the conference rather than there being an appropriate focus on it.

*“There is a critical need to be research-based now research is here and continuing to emerge. This means marrying the clinical researchers with researchers on the ground.”*

Dr Ann Goebel-Fabbri, Clinical Psychologist and Researcher, Joslin Diabetes Center, USA

3.8.3 The charity sector and medical research foundations are partly responsible for forging UK and international research partnerships. As the response and approach to identifying, treating, and preventing TIDE is novel, it is imperative that all academic, statutory and charitable funding sources are strategically developed and expanded. A feasibility study is currently underway led by Dr Christina J Jones and Dr Rose Stewart and funded by Diabetes UK and the University of Surrey. It provides parents with a range

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<sup>31</sup> APPG on Eating Disorders. Breaking the Cycle: an inquiry into eating disorder research funding in the UK. September 2021.

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of psychological educational interventions to support children and young people with type 1 diabetes with the aim of helping to prevent disordered eating in the first place, and to support parents in identifying potential T1DE factors. The PaRent InterventiOn to pRevent disordered eating among children with type 1 diabetes (PRIORITY)<sup>32</sup> is due to report in the near future and if it finds evidence of efficacy this study will help determine the validity of funding for a wider scale randomised control trial.

3.8.4 Research is international in nature and international funding and collaborations can test clinical research interventions in centres in a number of countries. International medical research foundations such as JDRF have a role and the potential to identify research gaps and international research partnerships.

This is important in conditions such as T1DE where the national population may be a relatively small number. Multisite centres in different countries also increase the opportunity for a wider diversity of participants both culturally and ethnically. While good work is being established, research collaboration in T1DE in lower middle-income countries is still lacking, consistent with much psychosocial international medical research. There is an opportunity here longer term if the right research skill, appropriate patient population and funding can be established.

3.8.5 The UK has the potential to be world leading in T1DE research. The structure of the NHS which is integrated with the National Institute of Health Research means that if funding is made available, clinical research can define best practice in T1DE treatment and prevention. The NHS England pilots have a fundamental purpose in developing and establishing the research base for clinical treatment.

Dr Marietta Stadler is a diabetes consultant and one of the leaders of the King's College London NHS England T1DE pilots. She is also a clinical researcher and funded by the National Institute for Health Research to deliver, along with people living with type 1, researchers and clinicians, a six-year research programme to identify integrated therapies and clinical interventions which deliver positive outcomes for people living with T1DE. The STEADY project<sup>33</sup> integrates Cognitive Behaviour therapy with diabetes self-management for people living with T1DE.

*"You can't have a bunch of doctors deciding on an intervention, you have to have the people who've lived with the condition involved. They know what the day-to-day challenges are, what would potentially prevent them seeking help and what healthcare professionals can do to best support them."*

Dr Marietta Stadler, NIHR Clinical Scientist, Diabetes Consultant, King's College London

Dr Helen Partridge is a diabetes consultant and one of the leaders of the Bournemouth COMPASSION NHS England pilots. As a result of the pilot, she and the team have been able to research and develop a new approach to screening for type 1 diabetes.

*"We therefore set to trial a new clinic proforma giving ownership of the diabetes consultation to the person with diabetes (PWD) allowing them to raise questions around weight concerns and body image while pairing this with measures of diabetes distress (DDS-2)<sup>34</sup>. We introduced a short guide to using the proforma to health care*

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<sup>32</sup>Parent Intervention to prevent disordered eating in children with Type 1 diabetes (PRIORITY): Study protocol for a feasibility randomised controlled trial - Jones - 2022 - Diabetic Medicine - Wiley Online Library

<sup>33</sup>STEADY I - Health Research Authority (hra.nhs.uk)

<sup>34</sup>Development of a brief diabetes distress screening instrument, Fisher et al; May 2008 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2384991/>

*professionals (HCPs) with support around language and communication skills. The guide helps to establish a therapeutic relationship in which the PWD feels able to share their thoughts, emotions and behaviours without fear of judgement, embarrassment and shame.”*

Dr Helen Partridge, Consultant in Diabetes at University Hospitals Dorset, COMPASSION project lead

3.8.6 As a fundamental principle of good practice research, the inquiry was told of the importance of involving children and adults with lived experience in the design of research trials.

*“Pilot studies are important; we need them to iron out kinks and ensure people engage with a full trial. For example, with the text message trial, we asked teens with type 1 to suggest frequency of messages, rate the jokes, asked what types of merchandise they would want and to feedback on study logo. We held exit interviews to see what they liked. It was an iterative process. We learnt that for the parent component, we needed to incorporate a weekly text reminder to send children a positive message and not just focus on food and numbers.”*

Dr Sarah Jaser, Director of Paediatric Psychology, University of Vanderbilt, USA

### **3.9 T1DE prevention lacks systematic framework and funding**

3.9.1 The inquiry found that no clinical framework or funding infrastructure focusing on the prevention of T1DE had yet been established. This is in part due to a lack of clinical consensus on diagnostic criteria, and the lack of a defined, NICE approved care pathway, consequently a systematic focus on prevention services has to date not been addressed.

A wider point around the prevention of all eating disorders was made by Dr Agnes Ayton, Chair of the Faculty of Eating Disorders at the Royal College of Psychiatrists:

*“Primary prevention of eating disorders needs to be part of the wider public health messages including prevention of obesity, healthy exercise, starting in schools and regulation of food and weight loss industries. The commercial determinants of health are increasingly recognised and people with eating disorders are exploited by the diet and weight loss industries.”*

3.9.2 Role of risk factor identification in prevention is key. Between eight and 36 percent of people with type 1 are reported to experience clinical and sub-clinical levels of disordered eating. Risk factors have been identified including having an existing eating disorder at diagnosis, having experienced previous psychological trauma, experiencing accompanying co-morbidities of depression and or anxiety. A family history of risk factors also plays a role in potential predisposition to the development of T1DE.

Negative judgement from healthcare professionals who lack the training and appropriate language-based approaches to support people with type 1 diabetes distress was also identified as a long-term factor which could trigger complications among those people with type 1 who feel alienated from treatment services that they feel they can trust.

Patients living with type 1 and T1DE who feel shame or at risk of blame for struggling to manage their type 1 diabetes are more at risk of not attending routine diabetes appointments. Those patients living with T1DE who fall into this category may only see health care practitioners once admitted to hospital with DKA. The inquiry heard that the rate of DKA admissions should be incorporated as a risk factor for T1DE. Dr Chris Garrett, Consultant Diabetes Psychiatrist and Research Fellow at King's College London reported on his research which was a study into people with type 1 diabetes who experienced recurrent episodes of DKA, compared to others living with type 1 without recurrent DKA<sup>35</sup>. Globally the difference between the two groups was the likelihood of having an eating disorder. The inquiry heard that treatment for DKA focuses on medical stabilisation and health care practitioners in secondary care (Accident and Emergency and General Wards) are not supported in understanding the reasons for the patient presenting with DKA, of which insulin omission T1DE can frequently be the cause. If hospital-based health care practitioners can be trained in identifying insulin omission as a cause, diagnosis and referral could be accelerated.

3.9.3 While screening tools exist for diabetes distress, there is no current overarching structure to agree the appropriate screening tools alongside the training and support for primary, secondary, and tertiary health care professionals, to apply, interpret and either refer or treat people with T1DE. A working group should be established to develop a framework for effective T1DE screening.

By developing a standard proactive screening initiative, the healthcare system can identify people at risk of T1DE and intervene before the condition reaches a critical juncture. Early identification not only prevents the exacerbation of T1DE but also alleviates the burden on specialised services.

Thus, the recommendation for heightened focus on screening strategies emerges as a pivotal component of a comprehensive approach to combating T1DE, ensuring timely and targeted intervention for improved patient outcomes. NICE recommends that all people over the age of twelve with type 1 diabetes receive nine care processes and structured education into the management of the condition shortly after diagnosis, followed by annual care checks covering each of the nine areas<sup>36</sup>.

The nine care processes recommended by the National Institute for Health and Care Excellence (NICE) for individuals over the age of twelve with type 1 diabetes are crucial for comprehensive management and monitoring of the condition.

- 1.** HbA1c (Glycated Haemoglobin): HbA1c reflects average blood sugar levels over a few months and helps assess overall diabetes control.
- 2.** Serum Cholesterol: Monitoring cholesterol levels is important as people with type 1 diabetes have an increased risk of cardiovascular disease.
- 3.** Blood Pressure: High blood pressure is more prevalent in people with diabetes and requires regular monitoring to prevent complications.
- 4.** Body Mass Index (BMI): Tracking BMI helps assess weight status and identify any issues related to underweight, overweight or obesity.

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<sup>35</sup>The psychopathology of recurrent diabetic ketoacidosis: A case-control study - Garrett - 2020 - Diabetic Medicine - Wiley Online Library

<sup>36</sup>Care processes - NDRS (digital.nhs.uk)

5. **Smoking History:** Smoking exacerbates the risks associated with diabetes, including cardiovascular problems, and efforts should be made to support smoking cessation.
6. **Serum Creatinine:** Monitoring kidney function through serum creatinine tests is crucial since diabetes is a leading cause of kidney disease.
7. **Urine Albumin/Creatinine Ratio:** Assessing the urine albumin/creatinine ratio helps detect early signs of kidney damage and manage kidney disease.
8. **Foot Risk Surveillance:** Regular foot examinations and risk assessments are necessary to identify and address potential complications, such as peripheral neuropathy or foot ulcers.
9. **Digital Retinol Screening:** Regular eye screenings can detect early signs of diabetic retinopathy, a complication affecting the eyes.

These care processes are recommended to ensure early detection of complications, optimal diabetes management, and timely intervention to prevent long-term health issues. Structured education shortly after diagnosis and annual care checks ensure that people with type 1 diabetes receive comprehensive support, knowledge, and monitoring in all these critical areas. By addressing these aspects, healthcare professionals can work collaboratively with patients to optimise their overall health outcomes and reduce the risk of complications associated with type 1 diabetes.

However, it should be noted, that there is no provision made for an annual mental health check despite the high prevalence of diabetes distress. The introduction of such a check the inquiry found, could help to identify those at risk of diabetes distress and early intervention support could help prevent the risk of psychological complications such as T1DE.

3.9.4 While screening tools can help identify risk factors or presentation of T1DE, Dr Miranda Rosenthal, consultant endocrinologist at the King's College London T1DE pilot, highlighted the need for population-based studies, which require integration of datasets to map prevalence, range of severity and therefore population-based funding approaches. Achieving consensus on diagnostic criteria is also an interrelated factor which would optimise the value of population-based studies of T1DE.

NHS England does not have a type 1 diabetes data registry, that collects data from patients and can be used for screening. NHS Scotland has had a system called SCI-Diabetes since 2002, which provides clinical information, support for screening and the provision of data for national and local audits. The value of a registry such as Scotland's is fundamental to identifying risk factors in patients for T1DE, as well as providing a joined-up approach in T1DE care, across disciplines.

**32. Type 1 diabetes and disordered eating: Parliamentary Inquiry**

*“During my work I have seen good evidence that healthcare professionals too often feel they need to be more skilled in recognising risk factors and that they believe there are limited resources. More research is needed with sub-critical people disengaging with services to help develop knowledge for healthcare professionals, so they are more able to recognise those at risk.*”

*“SCI Diabetes is doing good work in the field to provide an integrated overview of different care provisions however, more needs to be done. Risk factor identification and greater access to data like gender and HbA1c could help screen for risk and potentially open the door to identification and prevention.”*

Dr Kate Smith, Head of Division of Health Sciences, Abertay University, UK



## 4. Recommendations

A substantial portion of the NHS budget goes on treating diabetes, although there is limited data that differentiates between type 1 and type 2. The vast majority of money spent arises as a result of complications from diabetes, as opposed to treatment or management of diabetes.

The estimated cost associated with both the condition of, and complications arising from, type 1 diabetes varies wildly. That said, it is well established that the cost of complications from diabetes vastly outweighs the cost of treating type 1. It is thought that around 10% of health expenditure in England is due to diabetes, with near 80% spend on complications arising from diabetes<sup>37</sup>.

Whilst it is difficult to define the exact economic impact of diabetes on the health service, one study noted the additional cost of provision of hospital services due to diabetes comorbidities was £3 billion above that for non-diabetes, and that within this, type 1 diabetes has three times as much cost impact as type 2 diabetes<sup>38</sup>.

Due to the issues with identifying and treating people with T1DE already outlined, there is a lack of economic data pertaining directly to the associated cost of T1DE. Further work is urgently needed to understand the scale of money that could be saved, through effective identification and treatment.

These recommendations are made to take into consideration the broad areas of changes which have been identified. Each particular area requires a detailed and multi-stakeholder approach to implementation, with programme planning and funding made available.

### 4.1 International consensus secured on T1DE Diagnosis

- An international symposium of T1DE experts should be created to share best practice and create a working group on diagnosis and treatment
- A working group of international experts should agree a consensus on diagnosis and treatment

### 4.2 Update NICE/SIGN guidelines improving formal treatment pathways

- NICE and SIGN need to review and update their guidelines on type 1 diabetes and eating disorders, to include more guidance on diagnosing and treating T1DE

### 4.3 T1DE pilots funded and extended into regional centres of excellence

- Integrated Commissioning Boards should fund existing pilot projects at the end of the pilot timeline, subject to positive outcomes, converting them into regional centres of excellence for the treatment of T1DE

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<sup>37</sup>Hex N, Bartlett C, Wright D, Taylor M, Varley D. Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs. *Diabet Med*. 2012 Jul;29(7):855-62

<sup>38</sup>Stedman M, Lunt M, Davies M, et al Cost of hospital treatment of type 1 diabetes (T1DM) and type 2 diabetes (T2DM) compared to the non-diabetes population: a detailed economic evaluation *BMJ Open* 2020;10:e033231

#### **4.4 Increase awareness of T1DE**

- Greater awareness of T1DE needs to be raised in the media and amongst the diabetes/eating disorders health care practitioner population

#### **4.5 Reduce stigma in diabetes and eating disorders**

- Diabetes and eating disorder charities should run campaigns addressing stigma and reporting of conditions in the media. This should draw on NHSE's Language Matters: Language and Diabetes<sup>39</sup> guidance, which was produced to give practical examples of language that will encourage positive interactions and positive outcomes in people with diabetes, and be done in partnership with people with lived experience
- Charities should work with NHSE to create an addendum to Language Matters: Language and Diabetes on T1DE stigma
- Social media companies should further moderate pro eating disorder material and misinformation around body image and diabetes/T1DE

#### **4.6 Reduce incidence of T1DE**

- A systematic framework for preventing T1DE should be established. This includes structuring a methodology to screen for risk, using population analysis and a consensus on which surveys and tools HCPs should use to identify risk at an individual patient level
- HCPs should screen for T1DE risk factors at diagnosis of type 1 diabetes
- Medical histories should be cross checked for eating disorders at diagnosis

#### **4.7 Mental health assessment**

- Mental health assessments should become the tenth annual care check
- Support for emotional wellbeing for people with type 1 diabetes is needed - mental health support should be embedded in all diabetes clinics

#### **4.8 Transform NHS approaches to data capture and sharing, to improve clinical outcomes for T1DE**

- Establish a collaborative approach to knowledge and data sharing within the NHS, including across services, disciplines and specialisms
- Utilise knowledge and data sharing to enable identification and support for patients with T1DE
- NHSE needs to create a data registry for type 1 diabetes, modelled on Scotland's SCI-Diabetes

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<sup>39</sup>Language Matters: Language and Diabetes, NHS England; June 2018 <https://www.england.nhs.uk/wp-content/uploads/2018/06/language-matters.pdf>

- NHSE needs to create a category in data registry on T1DE
- NHS Scotland needs to create a category in SCI-Diabetes on T1DE
- Quantify prevalence of clinical and sub-clinical T1DE, through the use of data registries

#### **4.9 Increase international and UK research investment to evidence intervention efficacy**

- Existing research should be mapped, and research on unmet need should be commissioned
- More funding should be allocated for international T1DE research
- Research should be conducted into a range of interventions due to the complexity of the condition – international collaboration and funding is key

#### **4.10 Improve education and training for health care staff to help identify and treat T1DE**

- Improve Health Care Practitioner training in T1DE in primary and secondary care
- Training in recognising T1DE should be rolled out to all GPs
- Following identification of suspected T1DE, fast referral should be made to a regional specialist centre

#### **4.11 NHS workforce strategy and plan**

- A comprehensive NHS workforce strategy and plan to be developed that encompasses recruitment, training, and retention of mental health professionals specialised in T1DE

#### **4.12 Support resources and peer support**

- Existing moderated peer support offerings should be scoped so that a peer support offering for T1DE can then be developed
  - A moderated online and in-person peer support offering should be established, structured and funded fully
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## Sessions and Witnesses

A number of oral evidence sessions took place. They were thematic and a list of witnesses who contributed can be found below.

### Wednesday 8 June 2022

#### Topic: Introduction – what is T1DE, incidence, and research

Contributors: **Fiona Kennon**, Systemic Family Therapist, Adult Eating Disorders Unit Priory Hospital, Cheadle Royal & DWED; **Miranda Rosenthal**, Kings College Hospital; **Jacqueline Allan**, Trainee Clinical Psychologist & DWED; **Ariella Thompson**, case study; **Sophie Elizabeth Coleman**, Senior Lecturer, School of Psychology, University of Central Lancashire; **Marietta Stadler**, Kings College Hospital.

### Wednesday 20 July 2022

#### Topic: Lived experience

Contributors: **Lyney Choules**, case study; **Lesley and Neal Davison**, case study; **Lawrence Smith**, case study; **Anonymous**, case study; **Anonymous**, case study; **Anonymous**, case study; **Kathryn Boreux**, case study; **Ellie Rose Huckle**, case study; **Naomy Larkin**, case study.

### Wednesday 26 October 2022

#### Topic: NHS response

Contributors: **Sara Crowley**, Diabetes Transitional Care National Co-ordinator, NHS Wales; **David Hopkins**, Diabetes Consultant, Kings College London; **Helen Partridge**, ComPASSION Project, University Hospitals Dorset; **Professor Agnes Ayton**, ED Faculty Chair, Royal College of Psychiatrists; **Sarah Alicea**, Paediatric Diabetes Specialist Dietitian, Poole NHS Trust; **Kelly Carden**, case study; **Lesley and Neal Davison**, case study.

### Wednesday 11 January 2023

#### Topic: Sector response

Contributors: **Rose Stewart**, Consultant Clinical Psychologist & Diabetes Psychology Lead, Betsi Cadwaladr University Health Board, North Wales; **Carla Figueiredo**, Lead Mental Health Clinician for the Wessex ComPASSION Pilot; **Chris Garrett**, Liaison Consultant Psychiatrist, East London; **Chrissie Jones**, Associate Professor in Clinical Health Psychology, University of Surrey; **Sarah Jaser**, Director of Paediatric Psychology and Associate Professor of Paediatrics at Vanderbilt University in Nashville, USA; **Professor Ingrid Willaing Tapager**, Head of Diabetes Management Research, Steno Diabetes Center, Copenhagen; **Anthony Winston**, Consultant in Eating Disorders at the Aspen Centre, Coventry and Warwickshire Partnership Trust; **Ann Goebel-Fabri**, Clinical Psychologist and Researcher, Joslin Diabetes Center, USA; **Dr Lindsey Rouse**, Clinical Psychologist, NHS Bournemouth.

### Wednesday 23 January 2023

#### Topic: Raising the profile

Contributors: **Kate Smith**, Diabulimia Researcher, Abertay University; **Jeannette Söderberg**, Director of European Research, JDRF International; **Anonymous**, case study; **Deanne Jade**, Principle and Founder, National Centre for Eating Disorders UK; **Ann Goebel-Fabri**, Clinical Psychologist and Researcher, Joslin Diabetes Center, USA; **Bridget Turner**, Director, Diabetes UK; **Erin Akers**, Founder and CEO of Diabulimia Helpline USA; **Umairah Malik**, Clinical Advice Coordinator, Beat; **Professor Khalida Ismail**, Consultant Psychiatrist in Diabetes, Kings College Hospital.

## Written Evidence

The following written evidence was received:

- 1** All Wales Diabetes Implementation Group (NHS Wales)
- 2** Ayton, Dr Agnes, Royal College of Psychiatrists
- 3** Kar, Prof Partha, National Specialty Advisor, Diabetes, NHS England
- 4** Kennon, Prof Brian, Consultant Diabetologist and National Lead for Diabetes, NHS Scotland
- 5** MacLennan, Dr Kirsty, Consultant Clinical Psychologist Diabetes & Sexual Health, NHS Grampian
- 6** NHS England
- 7** Rouse, Dr Lindsey, Clinical Psychologist, T1DE Wessex NHS ComPASSION pilot

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*“I was diagnosed with type 1 diabetes at the age of three in 1990 and have had no psychological support in those 32 years. The expectation of how I was supposed to control my diabetes was so high from other people it was unachievable and unrealistic. I couldn’t reach perfect, so the only thing I felt I could achieve was being uncontrolled, so I developed an eating disorder and that became a coping mechanism.”*

Sara, on living with type 1 diabetes and T1DE

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