



Evaluation of Type 1 Diabetes Eating Disorder (T1DE) Services

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Evaluation of Type 1 Diabetes Eating Disorder (T1DE) Services

Insights Report

February 2026



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Disclaimer

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List of abbreviations

A&E	Accident & emergency
BMI	Body mass index
CBT	Cognitive behavioural therapy
CCG	Clinical commissioning group
DDS-2	Diabetes distress scale 2
DEPS-R	Diabetes eating problem survey - revised
DKA	Diabetic ketoacidosis
DSN	Diabetes specialist nurse
ED	Eating disorders
EQ-5D-5L	Health-related quality of life 5 Dimensions 5 Level Version (EQ-5D-5L)
GAD7	Generalised Anxiety Disorder 7
GP	General practitioner
ICB	Integrated care board
ICS	Integrated care system
MDS	Minimum Data Set
NHS	National Health Service
NIHR	National Institute for Health and Care Research
PHQ9	Patient Health Questionnaire 9
REVAL	Rapid service evaluation team
T1D	Type 1 diabetes
T1DE	Type 1 diabetes disordered eating
WSAS	Work and Social Adjustment Scale

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1. Executive Summary

People with Type 1 diabetes may be at increased risk of disordered eating, which may increase risk of elevated blood sugars (measured HbA1c), diabetes ketoacidosis (DKA), mortality and premature onset of complications such as retinopathy and nephropathy.

Responding to growing recognition of unmet need in this complex patient group, in 2019 NHS England commissioned a pilot of two integrated Type 1 diabetes disordered eating (T1DE) services. The key principle of the T1DE pilots was to provide integrated physical and mental health care in an effort to provide effective treatment and care for this patient group. The pilot was implemented during the COVID-19 pandemic, and a relatively small amount of service use data was available, leading to challenges in fully understanding the impact of the services. However, patients and staff were generally supportive of the service. Consequently, in 2022 NHS England provided 2 years of national funding to support five further T1DE pilot services across England delivering a national specification, but with flexibility to implement according to local context.

The NIHR-funded rapid service evaluation team (REVAL) at the University of Manchester conducted a multi-method evaluation to explore the early implementation (five new services) and on-going implementation (three existing services) of these T1DE services.

Implementation in all five new services was slower than anticipated for a number of reasons (as described below) and NHS England initially extended the pilot phase by 12 months. Subsequently, NHS England have committed to continue funding until March 2026.

Delays in local implementation slowed service development and patient throughput, resulting in limited numbers with adequate time on the care pathway, at the completion of the evaluation. Whilst the evaluation was ongoing two original services closed in their current form due to challenges in securing local funding from Integrated Care Boards (ICBs) once national pilot funding ended.

At the time of the agreed REVAL evaluation (October 2024) there were a total of 129 referrals to the five new services, resulting in 79 patients accepted on the care pathway. One service accounted for almost half of those receiving care. Using updated data from NHS England in June 2025 there were an additional 69 referrals of which 60 were accepted on the care pathway.

Integration of physical and mental health commonly used: integrated multidisciplinary team meetings (MDTs) to discuss individual patients on a regular basis; joint clinic appointments; clinical and peer supervision and facilitated access to other members of the team.

Several barriers to mobilisation and continued implementation were identified including staff recruitment due to required skillset, job insecurity (fixed-term contracts) and part-time roles, problems identifying backfill for existing job roles and barriers to working across different organisational boundaries (acute and mental health Trusts). Ongoing commissioning of the services was also identified as a significant concern due to the funding pressures and priorities of ICBs.

Staff and patients both recognised a need for the service. Staff recognised the potential for benefits in this high-risk population where integrated provision could provide care that was holistic, supporting patients to make gradual changes to impact positively on health and social outcomes.

Many patients reported being at 'rock bottom' prior to receiving care in the T1DE service. Patients, although predominantly from one service, reported largely positive experiences in T1DE services compared to previous experiences of care. All patients interviewed reported being well supported and that staff had a good understanding and knowledge of T1DE, enabling patients to be more open and honest. Patients also described how they felt that staff knew them as an individual and that care was tailored specifically to their needs. Outcomes important to patients included health, resilience, wellbeing and quality of life but also the skills, knowledge and confidence to cope rather than going back to behaviours that may be harmful.

Staff suggested that patients would require care from the team for at least 12 months, and discharge did not seem to have been discussed for most patients at the time of interview.

Health outcome data (to October 2024) were available for a small number of patients at the completion of the evaluation; only 23 completed both baseline and 6-month follow-up (with only 16-20 completing health measures). At 6-months, compared with baseline measures there was a mean 0.5% reduction in HbA1c from 11.8% to 11.3%. Improvements in other outcomes including diabetes distress, depression and functional impairment were observed at 6 months, but numbers were small. Measures all remained above the recommended clinical thresholds apart from the mean scores on the Patient Health Questionnaire (PHQ-9) which improved by 3.6 points to just below the threshold for moderately severe or severe depression. Using updated data to June 2025 and for those patients with 6-month outcome data (measures completed for 29 to 47 patients) there was a 0.97% reduction in HbA1c from 11.2% to 10.2%. Changes in other measures were comparable to October 2024 data. Additional quantitative data to June 2025 is presented as a part of an NHS England report.

The economic costs associated with staff pay and non-pay for running the service ranged from £149,830 to £294,848 with the cost per patient on the care pathway ranging from £8,190 to £29,081 during the implementation period (October 2024). However, this is likely to be an overestimate, and cost is expected to reduce over time. Using additional data to June 2025 the costs associated with running the service ranged from £211,124 to £415,481 with the per patient cost ranging from £8,147 to £17,074.

Overall, the integrated T1DE service was acceptable to staff and patients. Although the service involved managing a complex group of patients, many staff were very positive about the service they provided, and the learning and skills development involved.

Equally, patients reported positive experiences of the integrated care model in contrast to their previous experience of care.

The limited data collected during the pilot at the time of the evaluation means that strong statements about effectiveness are not possible.

Pilots of these type are necessary to provide evidence for later commissioning but face a paradox – the lack of evidence means that investment is necessarily time limited and bounded, which in turn means that insufficient time may be available to accrue enough long-term data to evidence the effects that would support expanded commissioning of the service. In the current financial context, services which improve quality of care for relatively small numbers of patients with very specific needs may be challenging to fund.

To ensure services are sustainable and commissioned at local level consideration should be given to alternative commissioning footprints and service delivery models, such as a service models planned nationally and delivered regionally by experts with the necessary skills and expertise, which offer different care pathways depending on patient need, including a greater focus on providing local teams with advice and support. Whilst cost effectiveness has not been assessed in this evaluation, the average estimated cost per patient and other challenges such as recruitment suggest that services may need to be commissioned on a larger footprint, like those of other specialist services.

Any new commissioning or service delivery models should seek to maintain favourable aspects (such as positive patient experience, as well as confidence and capacity building among staff) using a model more focussed on advice and support, rather than direct service provision, and delivered remotely.

2. Evaluation Context

Approximately 400,000 people in the UK are estimated to have Type 1 diabetes at any one time; around 10% are aged 20 years or less (Gregory 2022). Type 1 diabetes commonly manifests during adolescence with incidence peaks in early childhood and at puberty. A Type 1 diabetes diagnosis means initiation of insulin therapy and modification of eating habits to optimise glycaemic control.

Adolescence is also the most common period for the onset of eating disorders, although they may manifest throughout the life course. The Global Burden of Disease study estimated that in 2019, 700 people per 100,000 suffered from an eating disorder (95% CI 492 to 965 per 100,000); an increase of almost 15% from 1990 (Castel Pietra et al 2022). A systematic review and meta-analysis of 94 epidemiological studies estimated that lifetime prevalence of an eating disorder is 8.4% (95% CI 3.3 to 18.6%) for women and 2.2% (95% CI 0.8 to 6.5%) for men (Galmiche et al 2019). Beat Eating disorders (BEAT), a UK charity, estimate that approximately 1.25 million people in the UK have an eating disorder with a report by the Royal College of Psychiatrists (2022) showing that hospital admissions for eating disorders in the UK increased by 84% over a five-year period from 2015/16 to 2020/21.

People with Type 1 diabetes may be at increased risk of disordered eating. The increased focus on eating patterns and food intake required by people with Type 1 diabetes, alongside the need for daily insulin and negative experiences from their diagnosis, may impact on eating practices and related behaviours. A study from the Danish Registry for Diabetes in Childhood and Adolescence (506 adolescents with Type 1 diabetes; mean age 14.7 years; mean HbA1c 5.2%) reported that 34% of participants were considered to have one or more indicator of overeating, sub-clinical binge eating or clinical binge eating (Marks et al 2021). A recent systematic review and meta-analysis of 14 studies (mean age range 11.6 to 27.9 years) including 1391 patients with Type 1 diabetes showed that the relative risk of an eating disorder was 2.47 (95% CI 1.84-3.32) compared to 7688 nondiabetic controls. This risk was specifically increased for bulimia nervosa (RR=2.80, 95% CI 1.18-6.65) and binge eating (RR=1.53, 95% CI 1.18-1.98) (Dean et al 2024).

Insulin restriction or omission to promote weight loss is also a recognised issue in people with T1DE: this is sometimes called diabulimia (Coleman and Caswell 2020). Induction of hyperglycaemia for example through insulin omission can lead to weight loss but also serious health problems. These include increased risk of mortality, diabetes ketoacidosis (DKA) and premature onset of complications of diabetes such as retinopathy and nephropathy. The prevalence of insulin omission/misuse has been shown to be 10.3% (95% CI 8.3–13.0) with this behaviour being much more prevalent in females than in males (RR=14.21, 95% CI 2.66-76.04 for insulin omission; RR=6.51, 95% CI 1.14-37.31 for insulin misuse) (Dean et al. 2024). Previous systematic reviews have shown a lack of evidence-based approaches to support people with T1DE (Clery et al 2017). A recent Parliamentary Inquiry into T1DE conducted by Sir George Howarth and Theresa May and supported by the Juvenile Diabetes Research Foundation (now known as Breakthrough T1D: Type 1 Diabetes)

highlighted a number of challenges in implementing care: lack of formal diagnosis; lack of integration, training and funding of T1DE care; lack of support, information and awareness for those living with T1DE; little evidence on treatment for T1DE and a lack of a preventative strategy for T1DE.

Several recommendations were made to help address these challenges including improving treatment pathways; increased awareness of T1DE and a strategy for prevention of T1DE through screening; annual mental health assessment (in addition to existing Type 1 diabetes health checks); a collaborative approach to data sharing enabling identification of patients with T1DE; improved education and training for healthcare staff to identify and treat T1DE; and a workforce strategy to recruit, train and retain T1DE healthcare professionals (Howarth & May, 2024). Furthermore, a coroner recently issued an action to Prevent Future Deaths report calling on the UK government to provide joined-up care, after the death of a young woman who took her own life as a consequence of the challenges she faced in navigating the system for treatment of T1DE (Dyer 2024).

In response to growing recognition of unmet need and lack of evidence on how to manage this complex patient group, NHS England commissioned a pilot of two exploratory T1DE services in 2019. An evaluation of these pilots reported data on 69 patients accepted onto the pathway (Service 1 n = 23 and Service 2 n = 46) (Kerr & Wild, 2022). The pilot implementation and evaluation were conducted during the COVID-19 pandemic, and this, combined with the small amount of service use data available, limited conclusions that could be drawn. Despite this, there were statistically significant reductions in HbA1c of 2.3% (range: reduction of 7.1% to increase of 0.4%, n=11) and 2.5% (range: reduction of 8.9% to increase of 2.4%, n=14) in the two services after 12-months of follow-up. There were also improvements in other health outcomes (e.g. diabetes disordered eating, depression, anxiety) but numbers with recorded outcomes at each service were small and demonstrated wide variability. Patients and staff were generally supportive of the services delivered. Patients reported being satisfied with treatment received (74% agreed/strongly agreed) and provided positive feedback about their experience of the T1DE service during qualitative interviews (n=6). After the pilots, staff reported an increase in experience, skills, knowledge and understanding of T1DE, confidence in recognising and supporting T1DE, and satisfaction of working in T1DE. During interviews staff spoke about the benefits to patients, learning through joint (integrated) working, as well as increased skills, knowledge and confidence. However, they also reported emotional challenges in addition to challenges in implementation and sustainability of the service. More recently published data for the London T1DE service (Ismail et al. 2024) on 47 patients with 12-month follow-up showed a smaller but statistically significant reduction in HbA1c (0.92% difference decreasing from 11.4% to 10.5%, 95% CI 0.31 to 1.54%, p=0.005) than that reported in the original evaluation. Reductions were also seen, in a smaller subset of patients, for DEPS-R, PHQ-9 and GAD-7 (n=9 to 11) with the latter demonstrating a statistically significant reduction in anxiety.

In 2022 NHS England provided further national funding to support the establishment of five additional T1DE services. The NHS England Diabetes Programme requested an evaluation to gain insights into the implementation of the service and to understand early impacts. The

NIHR funded Rapid Service Evaluation Team (REVAL) at the University of Manchester was commissioned by NIHR to design and conduct the evaluation. This evaluation was delivered alongside a quantitative evaluation being undertaken by NHS England.

The current evaluation aims to explore the early (five new services) and on-going implementation (three existing services – originally two services of which one split into two), to inform on-going learning and decision-making for NHS England.

Aims of the evaluation were to:

- Describe service delivery models and how they were developed and are evolving
- Investigate whether service implementation is being achieved (compared to the NHS England service specification) and in a way that is acceptable to staff, and contextual factors that contribute to implementation progress
- Investigate how service delivery is being sustained, exploring any adaptations made to services over time with the aim of supporting on-going activity and enhancing service delivery
- Investigate the experiences of patients
- Explore the costs of the service against the clinical consequences for patients

3. Gathering Insights

This was a multi-site formative evaluation focused on generating rapid insights detailing the practical implications of the implementation of T1DE services from staff and patient perspectives.

3.1 Evaluation development

Evaluation development began in 2022, with scoping of the literature on Type 1 diabetes and disordered eating. To inform the evaluation design further, we met with stakeholders including the NHS England Diabetes Programme team. Other stakeholder related activities included:

- attending NHS England workshops for T1DE services on:
 - establishing referrals and pathways and engaging key stakeholders
 - data and reporting
 - commissioning
- attendance at the T1DE 5th national T1DE conference
- meeting with staff members (including clinical leads, NHS England programme managers, (ICB staff and other staff) to explore wider contextual factors surrounding implementation of the T1DE service. These informal discussions (mapping) provided insights into planned delivery of the services
- providing feedback to services via NHS England workshops
- setting up a patient, public and Voluntary Community and Social Enterprise (VSCE) study advisory panel to inform the evaluation and provide feedback on preliminary findings

REVAL is a rapid evaluation centre, and evaluations are generally completed in a 12-month timeline. In this case, timelines were extended to allow better capture of data, and a report and academic paper were submitted before sites completed data collection. However, at the time of peer review of the paper, additional data had been collected at all sites.

To ensure transparency, we present the data collected to October 2024 (the agreed REVAL evaluation timeline) alongside data collected to June 2025 (updated data provided by NHS England)

3.2 Exploring the wider context (mapping)

We conducted informal conversations (mapping interviews) with lead contacts to explore contextual factors surrounding implementation of the T1DE services. In total we conducted 9 mapping interviews involving 18 staff members (including clinical leads, NHS England programme managers, ICB and other staff) across seven services (two existing and five new services).

3.3 Staff interviews and survey

We invited staff involved in the delivery of care or management of the T1DE services to take part in qualitative interviews and an online survey to gather insights into the delivery and

impact of implementation of the T1DE services. Table 1 provides details of staff members who participated.

Table 1: Details of qualitative interviews / survey conducted

Timeframe	Interviewees/ survey respondents	Scope of interviews /survey	Number of services	Number of interviews
Sep 2023 – July 2024	<ul style="list-style-type: none"> • consultant psychiatrists • consultant diabetologists • clinical psychologists • specialist dietitians • diabetes specialist nurses • mental health nurses • other e.g. programme managers, administrators 	<ul style="list-style-type: none"> • T1DE service integration and implementation • barriers and facilitators to implementing the service • experience and acceptability • perceived impact on patients • commissioning of the service 	5 new 2 existing	18 new 7 existing
Jul 2024 – Jan 2025	Patients receiving/ who had received care from the T1DE services	<ul style="list-style-type: none"> • expectations and previous care • care and integration of the T1DE service • therapy/ treatment, outcomes and discharge • suggestions for improvement 	3 new 1 existing	8 new 1 existing
Feb – Mar 2024	Staff from new and existing services	Survey on views on implementation and delivery of T1DE service	5 new 2 existing	20 new 5 existing
Nov 2024	Staff from new services	Survey on views on implementation and delivery of T1DE service	5 new	20 new

The survey included the validated Normalisation MeASURE Development questionnaire (NoMAD) (Finch et al. 2018). NoMAD was designed to measure constructs of Normalisation Process Theory (NPT), which explores factors that support or inhibit embedding of new practices into normal care (May et al. 2009). NPT constructs include: coherence (how do individuals and groups make sense of new practices); cognitive participation (do participants see new practices as legitimate); collective action (what work do participants do to enact new practices); and reflexive monitoring (how do participants make sense of the effects of new practices).

Survey participants were also asked to complete the Acceptability of Intervention Measure (AIM), Intervention Appropriateness Measure (IAM), and Feasibility of Intervention Measure (Weiner et al. 2017).

All measures were scored on a Likert scale from strongly/ completely agree to strongly/ completely disagree for each statement and scored on a scale of 1-5 (where 5 represented strong agreement). Scores were averaged across respondents.

Staff were asked to complete the survey in February and November 2024 to assess changes in staff perspectives over time. The follow-up survey was only distributed to staff in new services due to closure of two of the three existing services by the date of the follow-up survey (see Table 1; Appendix, Table 1A).

3.4 Patient interviews

We also conducted qualitative interviews to gather insights from patients. In line with accepted procedures, patients were approached by members of the clinical team who provided them with information about the study (participant information sheet, consent-to-contact form). Individuals who were interested in taking part were asked to contact the study team by completing a consent-to-contact form.

3.5 Minimum Data Set

We formed a working group with NHS England data analysts who conducted a descriptive analysis on the Minimum Data Set (MDS). The MDS collected patient-level data from all services at baseline and at 3-monthly intervals. The dataset included demographic information including age and ethnicity. Clinical measures included:

- HbA1c
- Body Mass Index (BMI) calculated from reported height and weight
- DEPS-R (Diabetes Eating Problem Scale – Revised) (Markowitz et al. 2010)
- DDS-2 (Diabetes Distress Scale – 2) (Fisher et al. 2008)
- Generalised Anxiety Disorder Questionnaire (GAD7) (Spitzer et al. 2006)
- Patient Health Questionnaire (PHQ9) (Kroenke et al. 2001)
- EQ-5D-5L (a health-related quality of life measure) (Herdman et al. 2011)
- Work and Social Adjustment Scale (WSAS) (Mundt et al. 2002)

We also present data up to June 2025 as provided by NHS England alongside that from the agreed evaluation timelines.

3.6 Economic Analysis

We conducted a cost-consequences analysis to explore service resource use and associated cost data alongside interim changes in health outcomes to give insights into care costs versus health consequences. The REVAL team undertook an economic analysis using the anonymised aggregated clinical data from the MDS supplied by NHS England analysts and associated costing information.

Service implementation cost data collection

To collect information on staff input and other healthcare resources, pay and non-pay costs, a detailed questionnaire was distributed to key contacts in each service. For staff pay costs, roles included: consultant diabetologist, diabetes specialist nurse, diabetes dietitian, psychiatrist, psychotherapist, psychologist, eating disorder dietitian, eating disorder therapist, mental health nurse, medical consultant, project manager and administrative staff. These are expressed in terms of % full-time equivalent (FTE) and grade.

For non-pay costs, the questionnaire included items such as venue expenses, travel costs, IT equipment, evaluation and analysis, staff training (T1DE team), engagement activities, outreach and educational materials (external to the T1DE team), phones and mobile devices, consumables, communications about the service (including website setup and referral pathways), overheads and any additional unbudgeted items. Capital costs are excluded from this analysis.

Costing information was obtained from individual sites to October 2024. To update the economic analysis in line with the updated data from NHS England, we calculated the average monthly cost during the implementation period and extrapolated the costs to June 2025. As the extrapolation period was less than one year, costs were not inflation-adjusted.

3.7 Advisory panel

We formed an advisory panel consisting of four individuals with lived experience of T1DE identified via the Breakthrough T1D (formerly JDRF). Two health care professionals also agreed to participate (also via Breakthrough T1D). The advisory panel were consulted at a number of time points during the evaluation providing useful context around T1DE and input into participant information leaflets, distress protocols and staff and patient topic guides.

Details of the project were also presented to the Greater Manchester Applied Research Collaborative (GM-ARC) young persons advisory group at the start of the project. The group provided input to staff and patient topic guides.

The following sections summarise insights from those delivering and receiving care from the T1DE service. A formal academic output will be published in due course.

4. Insights

4.1 T1DE NHS England funding and REVAL extension

Existing services were established in March 2019 (NHS England initially provided two years of funding) in London and Wessex. In 2022 the Wessex site split into two (Bournemouth and Portsmouth). During the course of the REVAL evaluation two of the original pilots (Portsmouth and Dorset) closed in their current form due to difficulties acquiring further additional funding, from their respective ICBs responsible for local commissioning of NHS service, following the initial period of national investment.

In 2022 NHS England provided two years of funding for five new T1DE services based in Cheshire & Merseyside; Leicester, Leicestershire & Rutland; Humber & North Yorkshire; Norfolk & Waveney; and Coventry and Warwickshire.

Implementation in all five new services was slower than anticipated due to a number of challenges (see section 4.3) and NHS England initially extended the pilot phase by 12 months. Subsequently, NHS England have committed to provide additional funding until March 2026.

The delay in implementation meant that service maturity was behind schedule, as was throughput of patients resulting in a limited number of patients with adequate time on the care pathway, in turn limiting data for the MDS. For these reasons a 6-month 'active hibernation' phase was incorporated where elements of data collection were paused. A further extension to the evaluation was approved in October 2024 (to end of January 2025) as implementation of the pilots remained slow with some services only beginning to accept patients on the care pathway. In addition, some services suggested that patients should have sufficient time on the pathway (at least 6 months) before taking part in qualitative interviews. This further extension also enabled the collection of additional data for the health economic analysis.

4.2 T1DE service planning

In total 9 mapping interviews were conducted with 18 staff members (including clinical leads, NHS England programme managers, ICB staff and other staff) across seven services (two existing and five new services). Appendix 1 gives an overview from the mapping interviews for the new pilot services.

There was some variation in terms of where services were based. Of the new services two were based in eating disorder clinics, two in diabetes clinics and one in a mental health clinic with an onsite eating disorders unit. Clinical leads were specialists in the type of setting where services were based, although in some instances there were joint clinical leads with expertise in mental health or eating disorders and diabetes. One new service had a small pre-existing, but well-established T1DE service prior to receipt of NHS England pilot funding with a consultant in eating disorders as the clinical lead.

At the time of mapping interviews (July – October 2023) the members of staff recruited varied largely depending on where services were on the implementation pathway: some

services had not recruited any members of staff. All services aimed to include diabetes specialist nurses and specialist dietitians (either diabetes or eating disorder dietitians), most planned on employing a clinical psychologist however recruitment in some services proved difficult due to the required skillset. One service planned on having specialist eating disorder practitioners and a multidisciplinary team (MDT) co-ordinator. Another service struggled to get any local eating disorder input due to capacity issues but instead planned to meet on a regular basis with the service led by the consultant in eating disorders. Staff employed in each of the new pilot T1DE services at the time of collection of economic costing data (October 2024) are detailed in Appendix B. One of the existing services had Occupational Therapist input which they perceived to be particularly beneficial. Existing services also recommended the importance of having a project manager of which three of the new pilot services had costed into the service.

Most services planned to conduct initial assessments face-to-face but follow-ups using a hybrid model with the option of face-to-face or remote appointments depending on patient preference. One service had problems finding suitable clinical space and therefore planned to provide predominantly remote appointments. Services also reported additional challenges in terms of working across organisational boundaries, data sharing and research governance arrangements, which took additional time to resolve.

Integration between diabetes and eating disorder services was anticipated to take the form of MDT meetings, held weekly or two-weekly to discuss individual patients, joint clinic appointments (e.g. diabetes specialist nurse and dietitian or diabetes specialist nurse and psychiatrist) with patients, peer supervision and other mechanisms for building cohesive relationships within teams (e.g. by having a set day when all team members were in).

The mapping exercise provided limited detail in terms of therapy and treatment as a part of the T1DE service. This was in part due to the services still being developed and delivery staff still being recruited. However, it was thought that care would include setting small realistic goals for diabetes self-care using a variety of approaches: cognitive behavioural therapy (CBT) for diabetes or CBT-E for eating disorders, psychodynamic therapy, carer support, practical advice on optimising diabetes care and management and dietetic support.

Services anticipated patient numbers at any one time to range from about 12 to 25 but most found this difficult to estimate due to a number of factors (e.g. identification of T1DE, referrals to the service and engagement by patients). Patients were expected to be in the service for one to two years (or longer). Treatment was not expected to be time limited. However, there was an expectation that contact with patients would become less frequent over time. Some services planned to review progress periodically (every 3 months in one service; and every 12-18 months in another).

Outcomes collected as a part of the MDS were identified as important as well as reduced hospital admissions which most staff felt would be the basis for future commissioning decisions. It was felt that “diabetes outcomes would be better but not brilliant” (as evidenced in the earlier T1DE pilot services) but that wellbeing and social outcomes may be a better indicator of improvement. Some services planned on collecting additional patient outcomes via patient surveys, focus groups and the Friends and Family Test.

4.3 Staff insights into delivery and impact of early and on-going implementation

Staff insights were explored using data from the staff survey and from semi-structured interviews. Staff surveys were completed by 25 staff at baseline (20 from new services and 5 from existing services) and by 20 staff (new services) at follow-up. From September 2023 to July 2024 twenty-five qualitative interviews were conducted with staff in seven T1DE services (one existing service closed at the end of 2023). Interviews were conducted with a range of staff involved in the delivery and management of the T1DE services (seven from existing services and 18 from new services, Table 1).

Model coherence, implementation and acceptability

The survey showed that staff generally scored highly on all domains except for ‘collective action’ for the question ‘I can easily integrate the T1DE service into my existing work’ (average score 3.57). Staff also scored lower on the statement ‘The T1DE service seems easy to use’ (average score 3.92) in relation to the feasibility of T1DE (Appendix 1).

In interviews, many staff recognised the potential benefits of having an integrated service and how this impacted not only on their role within the T1DE service but also more widely (unintended consequences). Most recognised the need for the service (i.e. there was patient demand for the T1DE services) but found it hard to estimate what actual need was. Some felt it was not appropriate to screen for T1DE as there was a risk that services may become overwhelmed. Most services were currently not operating a waiting list. Others recognised that without the T1DE service some people may not get the support required because they would not meet criteria for eating disorder services.

The perceived benefits to patients from the staff perspective included improvements in health-related outcomes but also improvements in the process of care: in terms of their experience of interpersonal care (‘being heard’ and ‘listened to’, feeling supported) as well as more co-ordinated advice and support from professionals and improved continuity of care, seeing the same health care professional(s), during appointments.

- *“I think a lot of times what happens is, people in good faith, healthcare profession in good faith, five members, the nurse, the dietitian, the doctor and the psychologist, all say something slightly different, and then each of those pieces are correct standing alone, but when one person hears five ways of going to Rome, they get confused about which way to turn, and you need to have everyone pointing in the right direction and feeling listened to.”*

Staff in some services talked about good working relationships (such as ‘being close knit’) and how they valued working as a part of the T1DE team.

- *“some of it was similar to how I’ve joint worked with diabetes before but I think the benefit is...there’s a lot more benefit now because we’ve got, how shall I say, just more...it’s more embedded that we’re working...how closely we’re working together and things are really joined up.”*

Whilst most services initially focussed on referrals from diabetes and eating disorder services where T1DE services were located, one service planned to use an outreach model

based within primary care, meeting with general practices (and community diabetes specialist nurses under primary care but recruited through Trusts) to go through lists of diabetes patients to identify any eligible referrals.

- *“And I can see the bright eyes, and they are very excited there’s something of that sort to help people from the mental health and diabetes is coming up, and they see it as a value.”*

Training and delivering care within the T1DE service

For the survey question ‘sufficient training is provided to enable staff to implement the T1DE service’ staff reported a lower score (average score 3.69) compared to other questions in the survey.

In interviews, staff reported having little formal training in terms of T1DE specifically as the service was new, and no specific training existed. Most reported having completed training in Type 1 diabetes (Bournemouth Type 1 Diabetes Education Programme - BERTIE) and Medical Emergencies in Eating Disorders (MEED) guidelines. Some had done training in CBT-E and in motivational interviewing which was found to be useful. For diabetes staff this involved a move away from a medical model to a more ‘*holistic interview technique*’.

- *“learn new language and you learn new words and you learn new concepts and, you know, all the psychological stuff that... you’d no idea about.”*

Most T1DE specific training took the form of shadowing and learning from other team members, and from existing T1DE services (e.g. sitting in on clinics) which was found to be helpful. Existing services also talked about how they had been involved in the development of new guidelines (e.g. MEED) and developing a specific training package for T1DE. Staff members at some services talked about delivering short training sessions to other team members and to wider networks. MDTs were also a valued method for learning.

Staff described patients within the service as being a challenging group with complex needs and risks. Care was described as ‘holistic’ as there were no readily available standardised treatments and no real evidence base for effective treatments for T1DE. Proposed treatment / therapies/ support are shown in Table 2.

Table 2: Details of therapies / treatment/ support proposed at time of interviews

Service number	Key therapies/ treatments/ support proposed	Notes
1	<ul style="list-style-type: none"> • psychology – emotional support, counselling, CBT, coping mechanisms • led by patients and their goals (diabetes, diabetes-related) 	ED therapist still to be appointed
2	Key components: <ul style="list-style-type: none"> • psychology (tailored CBT, CFT, ACT); group therapy using 5Rs recovery model; psychoeducation • dietitian (diet plan) • psychiatrist • ongoing diabetes care 	
3	<ul style="list-style-type: none"> • psychology – CBT, CFT, ACT; psychoeducation • diabetes management • identify triggers causing eating difficulties which in turn affect diabetes 	
4	<ul style="list-style-type: none"> • psychiatry - CAT formulation • dietitian input • DSN input • small goal setting • holistic approach 	Limited at time of interview – no therapists
5	<ul style="list-style-type: none"> • psychological may draw on CFT or ACT • psychoeducation • approach based on eating disorder interventions e.g. motivational work; MANTRA; CBT-T; SSCM • diabetes management • diet planning/ dietitian support • small goal setting • not manualised, individualised, patient-centred 	
6	<ul style="list-style-type: none"> • psychological therapies – ED therapist, CBT-E, CBT • psychological diabetes support for trauma, burnout, stress • dietitian input • OT for social anxiety • walking alongside people 	No off-the-shelf approach OT for part of service
7	3 components: <ul style="list-style-type: none"> • psychiatry – psychodynamic or CBT approach, medication & monitoring • diabetology – medication, acute problems • psychotherapies – psychoanalysis for trauma; insulin stabilisation; sometimes family therapy 	No one-size fits all approach

ACT – acceptance and commitment therapy; CAT – cognitive analytic therapy; ED – eating disorder; DSN – diabetes specialist nurse; CBT – cognitive behavioural therapy; CBT-E – enhanced CBT; CBT-T – CBT ten; MANTRA – Maudsley Model of Anorexia Nervosa Treatment; OT – occupational therapy; SSCM – specialist supportive clinical management

Staff often referred to the importance of being non-judgemental and supporting patients to make small gradual changes. As a consequence, changes in health outcomes may be less easy to measure using existing outcomes or take longer to become apparent. In addition, the prevention of worsening, or maintenance of current levels, of health may only be demonstrated through comparison with a control group.

- *“but actually what I’ve noticed is the main thing is around engagement and rapport building and that actually the changes will probably happen with small goal setting, which is a bit more reflective of something like specialist support in clinical management that we would do in eating disorders...so it’s a bit more patient centred, patient led, rather than manualised treatment like...”*
- *“sometimes you’re just walking alongside people, and it’s helping them not to get worse”*

Barriers and facilitators to implementation of the T1DE service

In the staff survey there were mixed responses to the questions ‘Sufficient resources are available to support the T1DE service’ (average score 3.08) and ‘Management adequately supports the T1DE service’ (average score 3.69).

Several barriers to implementation of T1DE services were raised by staff. These included:

- access to suitable accommodation /space for the service
- staff recruitment which was seen as difficult due to skillset, job insecurity (short term contracts) and the part time nature of many of the job roles, as well as time taken to recruit to post
 - *“You know that that recruitment can take up to three months, if you have to advertise it out for two weeks and then you probably need another two weeks to get through shortlisting and interviews and offering. And that person, if they’re above a band six, has a three months notice period to give if you want them to leave. So already you’re five to six months in before you’ve even staffed it. And I think that’s major, something that really isn’t taken into consideration.”*
- identifying backfill for existing roles
- covering a large geographical area for some sites (although it was felt that hybrid ways of working could overcome this to an extent)
- working across different healthcare organisations (e.g. mental health and acute Trusts) and the difficulties this posed in terms of line management arrangements, contracts and different IT systems
- short-term pilots (projects) were sometimes seen as risky by the Trust

Facilitators to implementation of the service included:

- use of technology enabling appointments to be offered in a hybrid way - however, some highlighted that this could also be a barrier when patients were particularly

unwell and could not be taken directly to A&E if necessary or that technology and technological literacy may be a barrier

- working flexibly as a service e.g. some services talked about being able to see people in their own homes
- willingness and commitment of the team to making it work
- informal networking opportunities (for example a dietitians' network which helped to provide validation of what individual members of staff at services were doing), as well as support around boundaries and behaviour management
- alignment with ICB priority areas and having them on board as a co-applicant
- lived experience members providing input to service development
- MDT co-ordinator for co-ordinating appointments and documenting MDTs as well as a key link for patients

Further commissioning of services:

One of the major barriers identified in relation to the sustainability of the T1DE services was ongoing funding – particularly for those in existing services. These services talked about the frustration and difficulty of obtaining funding once the pilot phase finished. They reported that uncertainty of funding led to a stop-start service ('a hiatus in recruitment') as it was deemed unethical to provide care to patients when the T1DE service might close due to lack of funding, and that year-on-year funding was disruptive and increased clinical risk in patients. It was also felt that many clinicians did not possess the skills to write business cases for ongoing funding support, and that commissioners were looking for ways to reduce costs, with a focus on short term outcomes, rather than prevention of longer term diabetes complications, and therefore T1DE services would not be seen as a high priority area as they were deemed as a 'high cost, low volume' service. Ongoing funding was also recognised as important to new T1DE services.

- *“they’re so ill and they’ve got really high mortality and they really do die, they do, and they are actually quite expensive for the NHS with all the complications they’re going to run into, and you put all your blood, sweat and tears into it....And then if you see on the other hand this battle of trying to get this commissioned it’s rather disheartening”*
- *“I think we all know that mental health is always the first to go when there's austerity measures. Anything that looks at wellbeing that isn't quite as much hard sciencey is what goes. But also there's this, the technology takeover of diabetes at the moment means that I feel like probably a lot of ICBs think they're like, well, we can have psychology, or we can have pumps....So my worry is that when this pilot finishes, diabulimia will have had its moment in the sun....what's going to happen is that diabulimia won't be sexy anymore. T1DE won't be interesting anymore.”*

Despite this, one member of staff at one of the T1DE services mentioned how they had been approached by other eating disorder dietitians to try and establish their own local pathways for T1DE patients.

- *“What I have noticed is that since T1DE has become more discussed in the eating disorder world there are more services that are looking at linking in with diabetes teams to create a pathway without the funding, without the pilot. They’re just trying to make those links now and establish some form of joint working for this patient group. I’ve had quite a few dietitians [in other areas] reach out to me to say interesting what you’re doing, we’re looking at developing a pathway locally.”*

Outcomes and discharge

On the whole staff considered that the T1DE service worked well. They reported perceived positive outcomes in terms of diabetes (e.g. fewer hospital admissions for DKA, lower HbA1C) but felt that better outcomes would be seen in terms of wider psychosocial outcomes e.g. improved quality of life, socialising, better home and work life.

- *“it’s opening up life a bit, you know, kind of, that idea of building a meaningful life”*

One aspect that some staff at existing services recognised as being potentially problematic was discharge of patients, as there was sometimes a reluctance to discharge, particularly for staff within diabetes teams. It was also recognised that patients found discharge difficult and disliked the word ‘discharge’ and its connotations. Some members of staff felt it was important to prepare patients well in advance.

- *“[we] hadn’t really clocked that people with diabetes might not realise that this service is an entity that they will come in, have treatment and leave”*
- *“I think it’s hard for all of us, isn’t it, when do you discharge. I’ve spoken about discharge of patients not attending. I think that’s something we’ve got to be a bit tighter on because we’re so conscientious sometimes that we say, we’ll leave it a bit longer, we’ll leave it a bit longer.”*

Outreach and training other staff

Staff in existing services talked about training they had provided for new services through NHS England workshops, as well as training more widely for example:

- to the charity BEAT Eating Disorders
- developing videos for staff in inpatient wards
- training sessions for other health care professionals
- developing Medical Emergencies in Eating Disorders (MEED) guidelines on T1DE (https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr233---annexe-3.pdf?sfvrsn=c45bd860_14)

New services also reported having organised training/learning sessions with other NHS healthcare professionals such as general practitioners, hospital departments (including A&E), community and practice nurses, to share information and raise awareness of T1DE. For example, one patient talked about how the T1DE team had delivered a session to her local diabetes team after inappropriate comments were made. Another service developed a

'concept group' led by patients to promote T1DE, for example by developing a series of posters to increase awareness of T1DE amongst the general public, but also amongst clinicians and GPs.

- *“training with our medicine colleagues, we’re booked in to do some training just to turn round and say like, listen, the eating disorder thoughts, we’re actually validating them by saying certain things. So, changing our language for this client group is going to change moving forward”*

Experiences working with T1DE patients

Staff agreed with the questions 'I value the impact the T1DE service has had on my work' (average score 4.52) and 'I believe that participating in the T1DE service is a legitimate part of my role' (average score 4.75).

During interviews, some staff members talked about how good an opportunity it was to work in the T1DE service. Some also saw the wider benefits in being able to apply learning to other job roles (many worked part-time in T1DE) and how they had become more 'psychologically-minded' generally.

- *“I’m really seeing how beneficial that can be when you do have it [clinical psychology], not just with disordered eating but how beneficial it could be for some of our other clients struggling with other challenges”*
- *“...and it’s a model for medicine, I mean, how many conditions are there, you know? Rheumatoid arthritis, anything you care to mentioned that’s, any chronic disease, you know, ulcerative colitis, blindness, deafness, COPD, anything has got a huge psychological overload and this is, if you don’t deal with that, forget it, you’ve lost, you’ve absolutely lost. So it should be the model of the way going forward”*

Many saw the benefit of working within the integrated T1DE team and whilst it was recognised this could be a challenging group to work with, they felt that they were able to support patients by providing non-judgemental, holistic person-centred care to support small steps to progress patient goals. The integration of the teams (mental and physical health) meant that they were able to offer better targeted care by treating T1DE as a single entity rather than treating disorders separately.

- *“been quite difficult for us, is sometimes the sense of, you know, it can be quite sad, it can be quite a hopeless feeling sometimes that, even if they were to make some positive change, the patient is likely to have limited life expectancy, even though they’re young as well, because of the severity and the, sort of, chronicity of their unmanaged symptoms....So that’s been hard I think to still be very patient-focused and still be looking at, you know, what can we do to optimise quality of life....”*

Some of those who previously worked in diabetes teams initially found it difficult advising patients to do things that would not normally be recommended but felt this became easier over time.

- *“if somebody’s got raised ketones you’d be advising much larger amounts of insulin, and with this group that’s just not, they just can’t, they wouldn’t be able to do it we’re advising stuff that’s not normally recommended and that is difficult, getting your head around when you first start”*
- *“freaking out at that a few times, whereas now I’m a bit, like you know, two units are better than none”*

Many staff talked about the high level of risk and vulnerability of patients with T1DE. Some staff talked about how previously they had struggled with the language and ability to cope with this particular patient group.

- *“when people are saying oh you’re looking really unwell, she’s like brilliant. The little eating disorder voice in her head. And you’re coming from a point of concern and care and you don’t realise that you’re triggering the eating disorder thought”*

Others talked about the emotional toll and how patients would keep them awake with worry at night or over weekends. This risk was managed as a part of the MDT and staff members also had quick and easy access (via e.g. email, phone, WhatsApp groups) to others in the T1DE team. Peer support and clinical supervision were highlighted as being important to help manage stress and provide reassurance. Some staff in existing services also talked about the need to retain boundaries by setting ground rules for patients from the beginning.

- *“we in mental health are able to tolerate risk in terms of self-harm and suicide...likewise we had to tolerate high levels of ketones and glucose as part of the treatment initially and that would scare me”*
- *“I have to be really boundaried with my communication times, it’s very tempting when I’m at my other job, to respond to people. And I was finding that some people would email me, like a picture of their ketone meter, and say, look my ketones are seven, what should I do? Or...”*
- *“I feel like we do sit with a higher level of risk than perhaps we always feel comfortable with as working with eating disorders, and I suppose that comes from a lack of experience of working with diabetes as well as to how it’s managed and what the risks are.”*

NHS England pathway

Some staff from existing services acknowledged that the T1DE model in its current form was probably not sustainable in terms of being integrated to Trusts as business as usual due to funding issues and priorities of ICBs. It was also recognised there was not the staff capacity required. When asked what the ‘minimum’ might be in terms of staffing and infrastructure to sustain the service there was a lack of consensus in what this might look like. For example, one member of staff from an existing service suggested a small amount of time from a diabetes consultant (MDTs and advice); a very experienced dietitian (rather than a diabetes specialist nurse) with an extended role including prescribing and diabetes

technology, dietary assessments, meal planning, liaising with eating disorder services; and a diabetes psychologist for managing risk and structured therapeutic interventions. Another suggested a wider team including: consultant diabetologist; lead from eating disorder team (preferably psychiatrist rather than psychology led due to prescribing role); psychologist or eating disorder therapist; dietitian - possibly also a diabetes specialist nurse, occupational therapist and initially a project manager. Whilst another staff member suggested that it perhaps was not necessary for a different service but that a more flexible pathway was required e.g. integrating a skilled eating disorder practitioner to sit in the type 1 diabetes service. Another staff member suggested that the specialist T1DE training was the most important aspect.

- *“It has to come centrally, it absolutely has to come centrally. You know, you can’t have a service like this in every [inaudible], it’s just a) not necessary, b) far too invasive, I mean, it takes over your entire life managing these people.”*

The NHS England service specification was seen as good but in reality was more complex on the ground - there was a large investment initially in terms of getting services up and running (systems, policies and pathways) but obtaining and maintaining staff was difficult. It was also felt that commissioners were focussed on outcomes and were less aware of the complex process of implementation, in terms of staff recruitment and training and the engagement of patients

- *“they [NHS England] put some money in, and the intention was right, and it’s great that they’ve done it, but then the practical issues are really challenging, with the duration of time, trying to get secondments, the lack of coordinated training for the sites. Yeah, I think those are key things that, with the time again, you would hope were doing differently.”*
- *“something around engagement, just coming to appointments where a lot of these patients don’t engage with health professionals and have had really negative experiences in the past or experiences of being told off or feeling like they’re being told off. So I think some of them don’t trust or want to be involved in services, and the fact that they keep coming to appointments when historically they’ve just completely disengaged with services.”*

In addition, many services felt that an intervention of 12 months of care was unrealistic with the majority of services saying that length of time in the service would not be time limited.

- *“12 month intervention package is a myth. We were funded to do that, in reality it does not work, I think they need longer.”*

4.4 Patient insights into receipt of T1DE services

From July 2024 to December 2024 we conducted nine interviews with service-users from four services. Six interviews were with patients from one new service, and three patients each from three additional services (2 new, 1 existing) (Table 1). All interviewees were female and White/ White British ranging from 18-24 to 50-54 years old (3 <30 years, 3 30-40 years and 3 >40 years). Six were diagnosed with Type 1 diabetes in childhood or adolescence and the majority were diagnosed with an eating disorder in the last five years.

Expectations from the T1DE service and previous care

Previous experience of care was disjointed and very much based on a medical model with the Type 1 diabetes and eating disorder (and or mental health) treated separately, or, their eating disorder largely ignored. In the diabetes clinics patients felt there tended to be a focus on clinical parameters rather than on how individuals were feeling or coping. Some patients did not recognise they had an eating disorder but had been given the feeling that they were a 'bad' or 'poor' diabetic. This often resulted in individuals feeling isolated and sometimes disengaging from services.

- *"in the past a lot of consultants are only bothered about the numbers and they actually don't care and I think throughout my first probably ten, 15 years of having diabetes, I don't think anyone ever asked me, like, how I was or how I felt about any of it. I think it was all, yes literally like, well let's just tick off these numbers. Oh, they're all good. Oh yes. Yes, you're healthy on paper, therefore off you go."*
- *"heading [letter] was, like, poorly controlled Type...no, chronically poorly controlled Type 1 diabetic. And I'm like, that's really unfair to say because I am really trying my best."*

Prior to the T1DE service, patients used terms such as being at a point of 'burnout', wanting help to pull themselves out of a 'black hole' or how they were at 'rock bottom'. Others were seeking care to avoid developing later complications.

Generally patients had no prior expectations of the T1DE services and were unsure what the service would entail. Some staff members also reported a degree of ambivalence by some patients but felt this may have been down to maturity of the services. Most patients expected the service to be similar to previous experiences although one patient reported concern .

- *"I will be honest, my initial thought, I panicked a little bit. I thought maybe they'd take me away and put me in hospital."*

Experience of care and integration in T1DE services

All patients reported feeling very supported and that staff within the T1DE services had a good understanding and knowledge of T1DE and how interlinked their diabetes and eating disorder were, with many saying they felt that staff 'got it', that they felt understood and that staff listened to them in a non-judgemental way. This enabled patients to feel

comfortable and safe, allowing them to be more open and honest. They also felt that members of the T1DE teams knew them as individuals and care provided was tailored to their individual needs.

- *“it feels like they actually want what’s best for me instead of just what’s best for a patient - not focussing on numbers and data - interest in you medically, mentally and socially”*
- *“I feel like they understand me more, then it makes me actually, sort of, open up and talk more about what I’m thinking and feeling because the other times, if I’m like, well you don’t know who I am. You don’t care. I’m going to walk out this room and I don’t trust that you’re going to do X, Y and Z that you said you’re going to do.”*

Patients also reported that all members of staff were well-informed and they did not have to retell their story at each appointment.

- *“everybody’s on the same page and they’re all sharing information with each other so it’s great.”*

Some patients talked about the validation of their T1DE diagnosis and how it was important to them that they had a label and that their diagnosis was recognised. This made them feel ‘normal’ and that they were not alone or the only one.

- *“I felt like I was this freak on my own that was just the only person, like, struggling with these things and actually, understanding, it’s really nice that whatever I say, they never go, oh my god. They’re just like yes. So, I feel like the fact that I’m not...”*
- *“the validation thing was...as I said previously, was really important to me, made to feel that my thoughts, feelings and opinions mattered and they weren’t just dismissed and I wasn’t just another name on another piece of paper sort of thing, I was who I am.”*

In terms of integration of the service, the majority of patients felt the joined-up approach during appointments (e.g. diabetes specialist nurse and dietitian) worked well because the two conditions (Type 1 diabetes and eating disorder) were so interlinked. One patient described it as a ‘network’ rather than having to see two or three different specialists. Some felt that joint appointments could be a little overwhelming or daunting at first, and one patient did not feel joint appointments with the therapist worked because they felt rushed so they could also discuss their diabetes in the same appointment.

Therapy / treatment, outcomes and discharge

Therapy was limited in some services as not all staff had been appointed. However, patients appreciated the ability to choose options they felt they would benefit from (e.g. talking therapy; dietetic advice; diabetes advice). Services often worked at a pace to suit patients

(e.g. weekly or two weekly), generally working in gradual steps and offering practical tips and advice (e.g. how to manage on holiday). Services were very adaptable to needs and flexible in terms of whether appointments were face-to-face or online depending on patient preference. Patients also described how services were quick to respond via email and/or phone call. For example, one service acted as an intermediary with the general practice when a patient had problems with out-of-stock insulin pens.

- *“no one has ever fit the therapy to my needs rather than my needs trying to fit their therapy”*

Outcomes identified as being important to patients included health, resilience, wellbeing and quality of life. Some patients also talked about how their physical health could only start to change once there were improvements in mental health. Others felt it was important to gain skills, knowledge and confidence to cope rather than going back to adopting behaviours that might be harmful or self-sabotaging.

- *“I’d love to maintain that ability to put in different coping strategies rather than going to the ones that hurt me”*

Discharge did not appear to have been discussed with most patients and some expressed anxiety about the thought of discharge and the risk that they might become worse again. One patient felt that discharge would be approached in a positive way whilst another thought it could be isolating once the support was no longer there.

- *“to me I see it as being let go, that I’ll just spiral again. I feel like I’m stood in a black hole and they’ve got a rope around me and they’re holding onto the rope and stopping me from going any further. And if they discharge me, they’ve let go of that rope and I will just plummet into that black hole quite deeply and quite quickly.”*
- *“Because I think we can never underestimate how, when you’re having treatment, you’ve got maybe a wealth of knowledge and skills around you but when you come away from that, it can be really isolating.”*

Patients hoped that discharge would be approached in a gradual way with reviews every 6 to 12 months, information relayed to those taking over their care and the option to refer back into the service if necessary.

Suggestions for improvement

When asked about potential improvements to the service the majority of patients felt that if the service had existed when they were younger their health may have taken a different route in that they may not have formed habits which have become so entrenched they are difficult to break.

- *“growing up and then going through teenage years and stuff and body image is already hard enough when you’re 14, and then trying to manage your health full-time on top of that and feel like you have no one to talk to about it. Maybe if there was something like this maybe a little sooner, maybe my health would have taken a different path”*

Some also highlighted the pilots coming to an end as an issue given the time and effort to get services up and established but not giving services the time or opportunity to demonstrate their impact.

- *“That’s the fear, is that you put all this energy in and you never really had a decent shot at getting it going, that’s the worry.*
- *“it feels like all the stuff that they’ve worked towards and put in place and they shout about, and they should shout about it because the staff are amazing and what they’ve done has been really helpful, but they’ve got people that are still struggling and there’s no contact with them at all” [T1DE now service closed].*

Suggestions for improvement included group support, pain management or advice on pain, whilst another patient who had been offered occupational therapy as a part of her care felt that a ‘community based approach’ with practical day-to-day activities (e.g. shopping, eating out) would be helpful.

4.5 Economic Analysis and Outcomes from the Minimum Dataset

A cost-consequence analysis was conducted to provide insights into how the T1DE services impact on various measures, including activity and costs, and a range of health outcomes. The economic analysis primarily focuses on NHS costs associated with the implementation of the service and the improvements in health outcomes. The cost perspective is confined to the health system, excluding capital costs and patient-related direct and indirect costs (e.g. working days lost). It is important for decision-makers to understand that the total cost is likely to exceed the estimates provided in this analysis. While the figures are based on available data and specific cost components such as staff pay and non-pay resources, additional costs may exist that are not accounted for. These could include increased use of primary and secondary care resource use, as well as other indirect costs like loss of productivity or travel expenses. All the cost estimates provided are derived from actual, up-to-date figures collected directly from the services involved to align with the output from the MDS (i.e. October 2024). As these figures represent current expenditure, there is no requirement to adjust or inflate the cost estimates for analysis or reporting purposes.

Health outcome and economic costing data are also provided to June 2025 based on more recent NHS England data.

The health outcome data presented in this analysis were limited due to challenges in recruitment, resulting in a smaller-than-expected number of patients and limited follow-up

data. This makes it difficult to demonstrate measurable changes in health outcomes across different services at this time.

Additionally, the potential value of the service extends beyond immediate health outcomes including the prevention of future health complications via better diabetes management, which in turn may lead to reduced health care costs in the longer term.

The impact of T1DE services may also be reflected in broader areas such as capacity development within the healthcare system, improved stakeholder engagement, heightened awareness, and increased external outreach efforts. While these factors may not be immediately quantifiable, these effects are potentially important.

Staff employed and full-time equivalents at T1DE services

Table 3 shows the staff employed and full-time equivalents at each of the new T1DE services at the time of the evaluation in October 2024.

Table 3: Staff employed and full-time equivalents (FTEs) by T1DE services, October 2024

Service	1	2	3	4	5
Consultant Diabetologist	0.1	0.1	0.4	0.2	0.1
Diabetes Specialist nurse	0.4	0.5	0.7	0.8	1.0
Diabetes Dietitian	0.4	1.0	0.5		
Total diabetes FTE	0.9	1.6	1.6	1.0	1.1
Psychiatrist		0.1		0.25	0.1
Psychotherapist			0.6		
Psychologist	0.2	0.5	0.4	0.5	
Mental health nurse	0.4				0.4
Total mental health FTE	0.6	0.6	1.00	0.75	0.5
Eating disorder dietitian				0.8	0.6
Eating disorder therapist				1.0	1.0
Medical Consultant			0.08	1.8	1.6
Total eating disorders FTE	0	0	0.08	1.8	1.6
Project Manager	0.2				0.4
Admin	0.2	1.0	0.4		0.6
Admin – service co-ordinator			0.5		
Other	0.2				
Total admin/ other	0.6	1.0	0.9	0	1.0
Total All	2.1	3.2	3.6	3.6	4.2

All services employed a consultant diabetologist, diabetes specialist nurse and dietitian (specialist diabetes or eating disorder dietitian). All but one service had access to a psychologist, which instead employed a full-time eating disorder therapist. Three services had input from a psychiatrist and two from a mental health nurse. Most services also had administrative or project management support. Total full-time equivalents ranged from 2.1 to 4.2.

Estimated economic cost of service implementation across services

Using data up to October 2024 showed the economic costs for running the T1DE services varied significantly across regions, reflecting differences in population, resource use and service priorities. Service 4, recorded the highest total expenditure at £294,858, with a major portion allocated to Diabetes Specialist Nurses and Eating Disorder Dietitians (0.8 FTE). Service 4 also had the lowest cost per patient accepted on the care pathway at £8,191. Service 5 with the highest per patient cost (£29,081), had a total expenditure of £290,809 (Table 4a).

Service 1 reported a total expenditure of £149,830, predominantly allocated to staff pay for a Consultant Diabetologist and Diabetes Dietitian. Service 2 reported a total cost of £238,664, with the primary spending on Diabetes Dietitians. Service 3 reported a total cost of £197,336 with the primary spending on a Diabetes Specialist Nurse followed by a Psychologist. These figures illustrate the financial investment and varied cost drivers involved in implementing the service across regions, reflecting service-specific priorities and resource needs. Detailed costing information is provided in appendix B.

Table 4 1: Referrals, accepted on care pathway and costs by individual services (to October 2024)

	Service name				
	1	2	3	4	5
Referrals	16	26	17	56	14
Accepted on care pathway	12	10	11	36	10
Total cost to end Oct 2024	£149,830	£238,664	£197,336	£294,858	£ 290,809
Per patient cost on care pathway	£12,485.8	£23,866.4	£17,939.6	£ 8,190.5	£ 29,080.9

NA – Not Available

Table 4 2: Referrals, accepted on care pathway and costs by individual services (to June 2025)

	Service name				
	1	2	3	4	5
Referrals	16	45	27	76	34
Accepted on care pathway	14	25	25	51	24
Total cost to end June 2025*	£211,124	£336,299	£278,065	£415,481	£409,776
Per patient cost on care pathway	£15,080	£13,452	£11,123	£8,147	£17,074

*Cost data was available up to October 2025 while clinical outcomes are reported up to June 2025. To ensure comparability the average monthly cost was calculated and extrapolated for the remaining nine months.

Per patient cost was lowest Service 4 with the most patients accepted on the care pathway and the expectation would be that these costs would reduce once services become fully embedded and patient throughput increases which may lead to per patient costs equalising over time.

Analysis combining clinical outcome data to June 2025 with cost data to October 2024, extrapolated to June 2025 showed the total expenditure remained highest for Service 4. However, this service had the most patients accepted on the care pathway and

subsequently the lowest per patient cost (£8,147) (Table 4b). Service 5 had the highest per patient cost (£17,074) with a total expenditure of £409,776. From October 2024 to June 2025 three services (including Service 5) had a significant reduction in the per patient cost accepted on the care pathway - implementation in these services tended to be slower compared to the two services which were able to offer some form of service (albeit limited) in early 2024.

Referrals, accepted on care pathway and discharges to the T1DE services

Aggregated data were supplied by NHS England as a part of the MDS. Data was submitted by individual services on a three-monthly basis.

Table 5 a: Number of referrals, accepted on care pathway and discharge (by service and total), October 2024

Service	1	2	3 ^c	4	5	Total ^b
Referrals	16	26	17	56	14	129
Initial Assessment	15	14	14	37	13	93
Accepted on care pathway	12	10	11	36	10	79
Discharge ^{a,d}	5	5	5	23	5	40
6-month follow-up ^a	5	0	5	14	5	23

^a Due to data suppression numbers from 1-7 are presented as 5

^b Total may not equal the total across columns due to data suppression in some cells.

^c Includes some data from pre-existing T1DE service

^d includes those ineligible on assessment

Table 5 b: Number of referrals, accepted on care pathway and discharge (by service and total), June 2025

Service	1	2	3 ^c	4	5	Total ^b
Referrals	16	45	27	76	34	198
Initial Assessment	15	25	26	54	30	150
Accepted on care pathway	14	25	25	51	24	139
Discharge ^{a,d}	9	26	14	46	14	109
6-month follow-up ^a	5	5	9	18	9	46

^a Due to data suppression numbers from 1-7 are presented as 5

^b Total may not equal the total across columns due to data suppression in some cells.

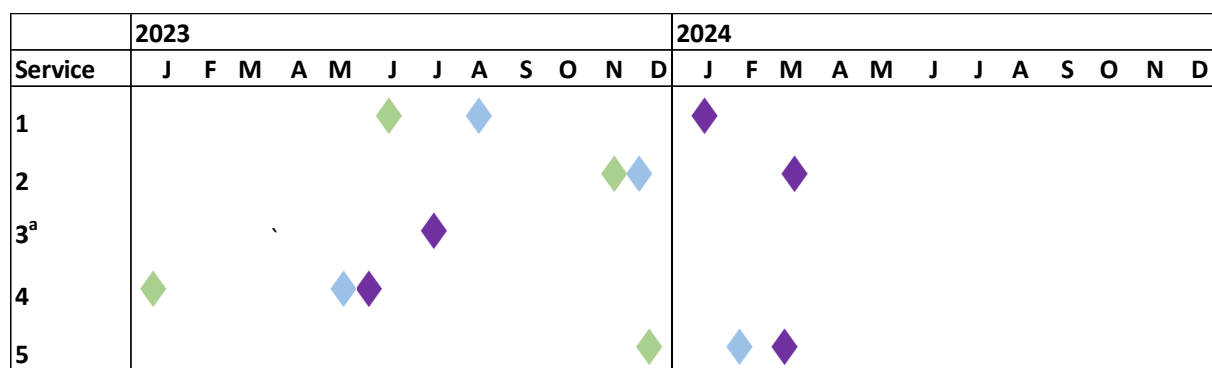
^c Includes some data from pre-existing T1DE service

^d includes those ineligible on assessment

The volume of available data was outside the control of the evaluation team. At the time of the evaluation numbers were small and it was not possible for NHS England data analysts to provide all information requested (e.g. 95% confidence intervals for change data in October 2024 or data on health outcomes by individual service due to small number data suppression).

During the agreed evaluation period (to October 2024) there were 129 referrals to the five new pilot services, 93 (72%) completed an initial assessment and 79/93 (85%) were admitted to a T1DE service (Table 5a). There were 67 patients still in a T1DE service at time of data submission. In June 2025, there were an additional 69 referrals with 60 patients accepted onto the care pathway (Table 5b). Number of referrals and those accepted on the care pathway and receiving care varied according to service with some services implementing the service earlier than others and without the full complement of staff. For example, the earliest referral to T1DE Service 4 was in January 2023 with the earliest admission in May 2023, meanwhile Services 2 and 5 did not have any referrals until late 2023 (Figure 1). The majority of referrals (October 2024: n=56, 43%; June 2025: n=76, 38%) and those accepted on the care pathway and receiving care (October 2024: n=36, 46%; June 2025: n=51, 37%) came from one service. The remaining services had a similar number of patients accepted on the care pathway (ranging from 10-12) in October 2024, increasing to 24-25 patients accepted onto the care pathway in three services. Of those accepted on the care pathway in October 2024 93% were female and 86% were White. In June 2025, the corresponding figures were 89% female and 92% White.

Figure 1: Dates of earliest referral, admission and discharge from T1DE services



◆ Date of earliest referral; ◆ Date of earliest admission; ◆ Date of earliest discharge^b

^a excludes referrals and admissions data as these were from pre-existing service in January 2023

^b includes those ineligible on assessment

At the time of evaluation in October 2024, 40 patients had been discharged from the service (Table 5a). This included 17 patients who were found to be ineligible on assessment, other reasons included non-attendance (n=8), self-discharge, completed treatment, moved out of area and death (all n<5). Six-month follow-up had been completed for 23 patients (14 from one service). For those still in the service (n=67) the median time ranged from 3 to 20 months reflecting the varying length of time T1DE services had been operational. The MDS submission from one service included data on patients from their pre-existing T1DE service which explains the longer median time in service.

Based on the data from June 2025, 59 patients were not accepted on the care pathway. A total of 109 had been discharged from the service including 33 patients who were ineligible on assessment. Other reasons for discharge included completion of treatment (n=21), non-attendance (n=23), self-discharge (n=16), moved out of area (n=12) and death (n<5). Six-

month follow-up was complete for 47 patients (18 from one service). For those still in the T1DE services (n=77) median time in the service ranged from 6 to 13 months.

Health Outcome Data from the Minimum Dataset

Due to the timing of the current evaluation our initial focus was on the presentation of clinical data collected during the early implementation of the service via the MDS. Data were only available for a small number of patients who had completed both baseline and 6-month follow-up (n=16 to 20 depending on outcome measure in October 2024; n=29-47 depending on outcome measure in June 2025). Change in health outcome measures are presented for those with data at baseline and at 6-month follow-up at both time points (Table 6).

In October 2024 the key clinical outcome, HbA1c, showed a slight improvement with a mean reduction of 0.5% (from 11.8% to 11.3%) at 6-months. The DEPS-R scale, which has a clinical threshold of 20 or more to identify T1DE patients, had a high mean score of 47.1 at baseline decreasing to 41.6 at 6-months. At baseline other health outcomes (GAD7, PHQ9 and WSAS) had higher mean scores than recommended clinical thresholds. At 6-months there was a positive reduction in all measures, however, all measures remained above the clinical threshold, except for the mean score on the PHQ-9 which improved by 3.6 points (from 18.3 to 14.7) to just below the clinical threshold of 15 indicative of moderately severe or severe depression.

Using the data up to June 2025 from NHS England there was a further mean reduction in HbA1c to 0.97 (from 11.2% to 10.2%, 95% CI -1.61 to -0.33). There were also reductions in the scores on the DDS-2 (-0.60, 95% CI -1.11 to -0.08) and the DEPS-R (-5.05, 95% -9.32 to -0.77). Changes in other health outcomes were of similar magnitude to those reported in October 2024.

There was a slight positive improvement in utility values measured by EQ-5D-5L, increasing from 0.46 to 0.47 using data from October 2024 and from 0.65 to 0.66 using data from June 2025. In the absence of a comparative group, we assume that the health-related quality of life would have otherwise remained unchanged (counterfactual).

Using the 'area under the curve' approach, we calculated the QALYs gained over six months and the resulting QALY difference, which was 0.0025 in both October 2024 and June 2025 (Figure 2). This QALY difference represents the average improvement in quality-adjusted life years for the entire group over the six-month period.

Table 6 a: Health outcome measures from the Minimum Dataset at baseline and 6-month follow-up (October 2024)

Consequence	N at both time points	Mean at baseline	Mean at 6-month follow-up	Mean difference from baseline ⁺
HbA1c (mmol/mol)	20	105.5	100.2	-5.30
HbA1c (%)	20	11.8	11.3	-0.50
BMI (kg/m ²)	20	23.1	23.2	0.09
DDS-2*	16	N/A	N/A	N/A
DEPS-R	17	47.1	41.6	-5.44
GAD7	17	13.8	12.4	-1.41
PHQ9	17	18.3	14.7	-3.64
EQ-5D-5L	19	0.46	0.47	0.01
WSAS	17	21.2	17.9	-3.30

⁺ 95% confidence intervals not available from NHS England for agreed REVAL evaluation timescale

* Scores on DDS-2 were unavailable due to incorrect scoring at one service

Possible scores and clinical thresholds – figures in bold indicate those above clinical thresholds

DDS-2: scored 1-6, clinical threshold 3+ used to indicate high distress

DEPS-R: scored 0-80, clinical threshold 20+ used to identify T1DE patients

GAD-7: scored 0-21, clinical threshold 10+ to identify generalised anxiety disorder

PHQ-9: scored 0-27, clinical threshold 15+ indicative of moderately severe or severe depression

WSAS: scored 0-40, clinical threshold >10 indicate significant functional impairment

Table 6 b: Health outcome measures from the Minimum Dataset at baseline and 6-month follow-up (June 2025)

Consequence	N at both time points	Mean at baseline	Mean at 6-month follow-up	Mean difference from baseline	95% CI
HbA1c (mmol/mol)	47	98.5	87.9	-10.6	-17.57 to -3.58
HbA1c (%)	47	11.2	10.2	-0.97	-1.61 to -0.33
BMI (kg/m ²)	46	23.9	24.2	0.32	-0.09 to 0.74
DDS-2	31	4.89	4.29	-0.60	-1.11 to -0.08
DEPS-R	32	46.1	41.1	-5.05	-9.32 to -0.77
GAD7	32	13.7	12.8	-0.88	-2.23 to 0.48
PHQ9	32	16.2	14.8	-1.34	-3.82 to 1.14
EQ-5D-5L	29	0.65	0.66	0.01	-0.05 to 0.07
WSAS	32	19.5	17.5	-2.00	-5.16 to 1.16

Possible scores and clinical thresholds – figures in bold indicate those above clinical thresholds

DDS-2: scored 1-6, clinical threshold 3+ used to indicate high distress

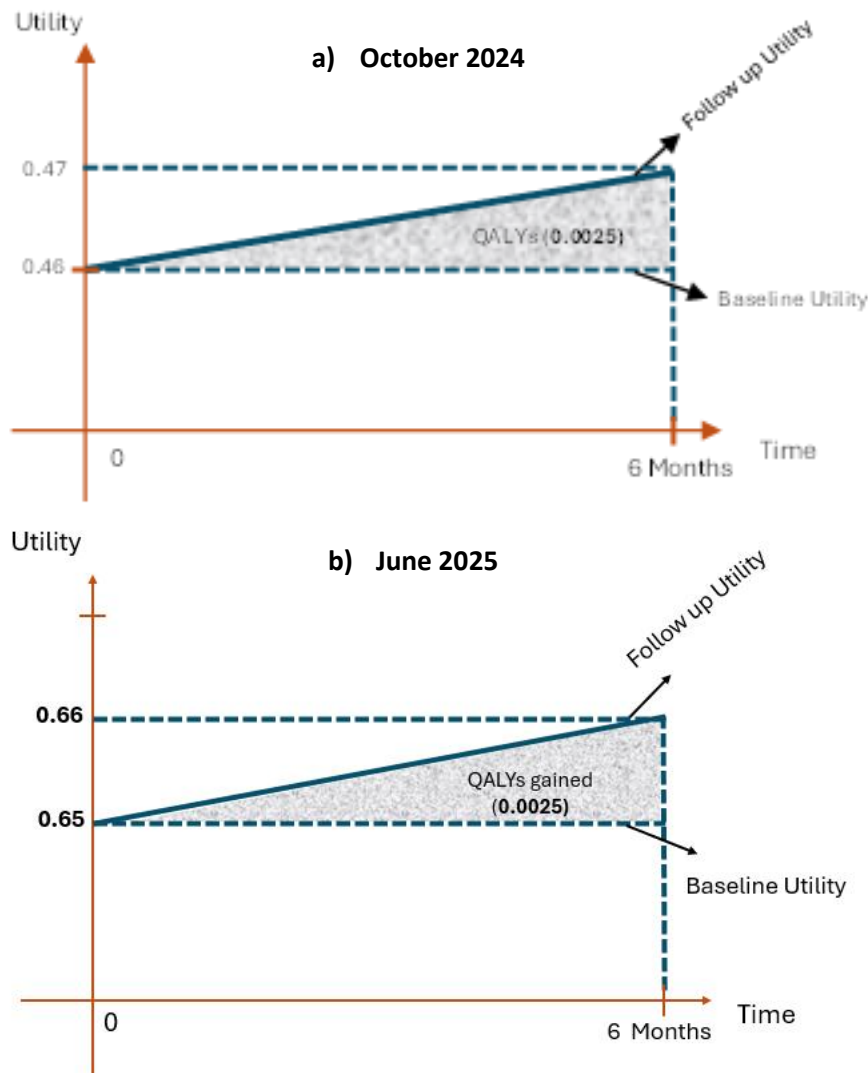
DEPS-R: scored 0-80, clinical threshold 20+ used to identify T1DE patients

GAD-7: scored 0-21, clinical threshold 10+ to identify generalised anxiety disorder

PHQ-9: scored 0-27, clinical threshold 15+ indicative of moderately severe or severe depression

WSAS: scored 0-40, clinical threshold >10 indicate significant functional impairment

Figure 2: QALYs accrued over six months based on EQ-5D-5L utility scores for a) October 2024, b) June 2025



4.6 REVAL and previous Insights Health Economics evaluation

Compared with the earlier evaluation of existing pilot services the number of patients accepted on the care pathway and receiving care was slightly higher (October 2024, n=79 with an additional 60 patients to June 2025; previous evaluation n=69). The previous evaluation recruited patients from March 2019 to July 2021 (28 months) including during the Covid-19 pandemic. The current evaluation included patients recruited up to October 2024 (with additional data to June 2025) however services in the different regions began recruiting patients at different times due to delays and challenges with set up in each of the services. Services will continue to accrue further data until March 2026 following the continued funding by NHS England.

The previous evaluation reported data for those with health outcomes after 12-months of follow-up whilst the current evaluation could only report health outcome data at 6-months of follow-up (12-month data will be available from an NHS England report). In the current

evaluation there was a smaller reduction in HbA1c of 0.5% to October 2024 and 0.97% to June 2025, compared to reductions of 2.3% and 2.5% in the earlier pilots, this may be due to the small numbers and the shorter length of follow-up.

Table 7 shows the difference in health outcome measures between the two evaluations. Baseline values were more severe for all measures, with the exception of HbA1c, in the current evaluation compared to those in the previous evaluation. The previous evaluation showed greater reductions in all measures compared to the current evaluation with the exception of the Work and Social Adjustment Scale (WSAS). However, numbers completing the follow-up in both evaluations was small, meaning that comparisons should be made cautiously.

More recently published data for the London T1DE service (Ismail et al. 2024) on 47 patients with 12-month follow-up showed a smaller but still statistically significant reduction in HbA1c (0.92% difference decreasing from 11.4% to 10.5%, 95% CI 0.31 to 1.54%, $p=0.0047$) than that reported in the original evaluation, but similar to the current evaluation using 6-month follow-up data to June 2025. Reductions were also seen in the London T1DE service for DEPS-R, PHQ-9 and GAD-7 the latter demonstrating a statistically significant reduction in anxiety.

In the two previous pilot services, the total costs, including initial setup expenditures, amounted to £414,987 and £215,035. Over an 18-month period (1st March 2019 to 31st July 2021), the services were provided to 46 and 23 patients. Despite the difference in total costs and patient numbers, the per-patient costs were comparable, at £9,021.50 and £9,349.30. This was higher than the T1DE service cost per patient for one of the new T1DE services (£8191 to October 2024 and £8147 to June 2025) but lower than other pilot T1DE services in the current evaluation. This may be due to the maturity of these services at the time of evaluation.

Staff members reported many similar issues to those found in the current evaluation with the most important aspects of the service identified in the staff survey being joint (integrated) working, MDT meetings and access to expert advice and support.

During interviews and from comments in the staff survey, staff spoke of increased skills, knowledge and understanding of T1DE through joined up working – this does not appear to be reported to the same extent in new services in the current evaluation possibly due to timing of staff interviews which were conducted at the beginning of service implementation. Nevertheless, staff in the current evaluation appreciated the joined up working approach through MDTs, as well as informal team networks and team mix, with easy access to other team members.

Staff members in the previous evaluation and those from existing services in the current evaluation talked of the emotional challenges working with this high-risk and complex patient group with a number of patients in existing services having required inpatient admissions. In the current evaluation this scenario had not arisen for new services at the time of interviews, but both evaluations highlighted the importance of clinical supervision and peer support.

Similar issues were reported in terms of challenges around the implementation and sustainability of the services namely: staffing, backfill of posts, working across different IT systems, space and ongoing commissioning. By the end of the current evaluation two of the three (one original pilot split into two) existing pilot services had closed in their present form due to difficulty in obtaining ongoing funding from their ICB.

Overall, 73% of patients in the previous evaluation reported being satisfied with the treatment received and recognised the importance of the integrated care (diabetes and mental health care) received from the T1DE services and the skills and knowledge this brought. They also reported improved outcomes in terms of health and wellbeing. Patients found remote consultations more difficult, particularly during the Covid-19 pandemic when remote consultations were relatively new. This did not appear to be an issue in the current pilots which were offering a choice of face-to-face or online consultations depending on patient preference. In the current evaluation 'validation' was important for a number of patients, being given a recognised diagnosis of T1DE, and the understanding and knowledge that this diagnosis brought with it (healthcare professionals 'got it') enabled an open and honest relationship with T1DE services.

Table 4: Comparison of health outcome measures from earlier evaluation and current evaluation

	Previous evaluation: 12-month follow-up				London service: 12 months follow-up*				Current evaluation (October 2024): 6-month follow-up				Current evaluation (June 2025): 6-month follow-up			
	n	Mean baseline	Mean follow-up	Mean diff	n	Mean baseline	Mean follow-up	Mean diff	n	Mean baseline	Mean follow-up	Mean diff	n	Mean baseline	Mean follow-up	Mean diff
HbA1c (%)	25	12.2	9.7	-2.5	47	11.4	10.5	-0.92	20	11.8	11.3	-0.5	47	11.2	10.2	-0.97
DEPS-R	16	35.2	28.3	-6.9	11	39.3	32.5	-6.8	17	47.1	41.6	-5.4	32	46.1	41.1	-5.1
GAD-7	17	11.5	8.81	-2.7	9	11.8	7.7	-4.1	17	13.8	12.4	-1.4	32	13.7	12.8	-0.9
PHQ-9	18	15.3	10.6	-4.7	11	14.4	12.3	-2.1	17	18.3	14.7	-3.6	32	16.2	14.8	-1.3
WSAS	13	17.7	14.8	-2.9	n/a	n/a	n/a	n/a	17	21.2	17.9	-3.3	32	19.5	17.5	-2.0

* some overlap of data from previous evaluation

n=number; DEPS-R: Disordered Eating in Diabetes – Revised; GAD-7: Generalised Anxiety Disorder; PHQ-9: Patient Health Questionnaire; WSAS: Work and Social Adjustment Scale. Figures in bold are above published clinical thresholds.

4.7 Limitations of the current evaluation

There were several limitations in the current evaluation. Firstly, implementation and set-up of services was much slower than anticipated, and as a consequence the number of patients recruited to T1DE services was low. This had implications in terms of health outcome data and economic analysis, but also in terms of those that could be invited to patient interviews.

Secondly, services were asked to upload data to the MDS on a three-monthly basis, this meant there were limited numbers of patients with available 6-month follow-up data, despite the additional data provided to June 2025. In addition, cost data was not available for the full period for which clinical outcomes were collected. As a result, cost estimates from October 2024 onwards were extrapolated.

Thirdly, patients were approached by staff at local T1DE services to invite them to take part in qualitative interviews, as a consequence T1DE staff may not have approached those they deemed as unsuitable for interview e.g. one service felt patients should be in the service for at least 6 months before being approached. Given the low numbers recruited to services this reduced the potential number of eligible patients for interview further.

Fourthly, it was not possible to incorporate a comparison or control group, therefore it is not possible to demonstrate changes in relation to those not receiving the T1DE service.

Finally, patient interviews were conducted primarily from one service, which makes it difficult to draw conclusions about how patient experience may vary depending on how services were configured. However, patients interviewed at each of three other services appeared to report similar experiences.

5. Implications for ongoing and future service delivery

- Overall, the integrated approach in T1DE services appears to be acceptable by both staff and patients. However, many staff interviews at new pilot services were conducted at an early stage of implementation and many were newly appointed. It is possible that views and experiences may change over time. In addition, the number of patients was small, and patient views and experiences were based predominantly on those from one T1DE service, yet staff and patient experiences were broadly similar to those reported in the previous evaluation.
- This evaluation highlights that the set-up of services takes time and is intensive. Several challenges were encountered by all services including staff recruitment, backfill and governance issues for across Trust working. Two services opted to provide some form of service at an early stage despite not having a full complement of staff. This meant the level of therapy/treatment was restricted but some form of support was available to patients if required.
- Services require time to gain knowledge, understanding and confidence (training through learning by experience and from other services) to work with this high-risk group and facilitating the need to build trust and relationships with patients.
- Due to the high level of risk, services focussed on gradual changes in patient behaviour. Outcomes, as measured in the MDS, may take longer to observe than in other patient groups. Nevertheless, the reduction in HbA1c was highlighted as an important finding by clinicians working in the services and would potentially lead to a reduction in complications. However, cautious interpretation is required, because the estimates are based on small numbers and cannot be confidently attributed to the T1DE investment.
- Benefits extend beyond those reported in the MDS and other health data outcomes. For example, staff talked about approaching all consultations incorporating both physical and mental health using the skills and knowledge they had developed as a part of the pilot. Some services also provided training sessions to other networks and services to help raise awareness of T1DE and T1DE services (e.g. to healthcare professionals in primary care - GPs and practice nurses, as well as staff in A&E departments).
- Longer term benefits are not captured by the data available to the evaluation. These may include the prevention of future health complications via better diabetes management, which in turn may lead to reduced health care costs in the longer term.

- Uncertainty around funding made it difficult to maintain a stable service with some delaying or halting patient recruitment until additional funding was in place. Whilst it was outlined in the NHS England guidance for expressions of interest that services would be expected to commit to developing plans for a sustained service, further support around developing business cases would be useful.
- Pilots for low volume, high cost services are innovative, but also risky when there is a limited evidence base for outcomes and impact. Starting small makes sense, but sufficient time must be given to accrue health outcomes in order to generate evidence of service impact.
- The proportion of patients referred but not admitted to services was relatively high and varied across services. Feedback to NHS England from clinicians in services was that referrals were actively encouraged, however, with no formal definition of T1DE the criteria for acceptance may have differed across services. For example, some patients may not have had a dominant presentation of T1DE, whilst for other patients it may have been dependent on the availability of other (more appropriate) local services.
- As more data becomes available over time outcomes related to additional healthcare resources, such as inpatient stays, hospital admissions for diabetic ketoacidosis (DKA), A&E admissions and other outcomes from primary and secondary care datasets should be investigated.
- The T1DE service is a low volume, high cost service involving a high-risk group of patients. This makes it challenging to integrate into a 'business as usual' model at Trust and ICB level in its current form (two of the existing pilot services closed during the current evaluation). Consideration should be given to the minimum in terms of staff and infrastructure necessary to deliver T1DE services and to what sort of model of delivery would work best. For example, a specialised service model whereby services are planned nationally and delivered regionally by experts with the necessary skills and experience may be an option. Such an example might be based on something like the maternity services model for women at risk of complications during pregnancy (<https://east-midlands-maternal-medicine-network.nhs.uk/>). This model offers a number of care options including: advice regarding pregnancy care, shared care with local teams or care delivered by maternal maternity centres. Specialist topic MDTs may also be attended by all clinicians caring for pregnant women.
- Given the lack of knowledge and confidence in identifying T1DE amongst healthcare professionals (Tan & Spector-Hill, 2021; Brewster et al, 2020) consideration should be given how best to retain and utilise staff recruited to pilot services as they have

gained invaluable knowledge, understanding, experience and skills working with this specific group of patients.

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Appendix 1: T1DE services: Mapping interviews overview (new services)

	Service name				
	1	2	3	4	5
Clinical lead(s) speciality	Diabetes	Diabetes x 2	Eating disorders	Psychiatry & diabetes	Diabetes & psychiatry
New or existing service	New	New	Pre-existing	New	New
Method of delivery (online/ face-to-face)	Assessment face-to-face assessment Treatment choice of face-to-face or remote	Assessment remote Treatment remote	Assessment face-to-face Treatment choice of face-to-face or remote	Assessment face-to-face Treatment choice of face-to-face or remote	Assessment face-to-face Treatment choice face-to-face or remote
Location of service	Diabetes clinic	Online	Eating disorder clinic	Mental health clinic	Eating disorder clinic
Key staff in service at time of mapping interviews (see Appendix B for staff in service at time of evaluation)	Diabetologist Psychologist (ED background) Diabetes specialist nurse Diabetes specialist dietitian	Diabetologist(s)	Consultant in Eating Disorders Senior specialist nurse – diabetes and eating disorders	Diabetologist Psychiatrist Diabetes specialist nurse Eating disorder dietitian	Diabetologist Psychiatrist Eating disorder practitioner
Expected numbers in service	10-12		24	Unsure	Unsure
Additional patient outcomes	Focus groups – patient experience	Mental health Physical health Social outcomes	Diabetes complications Quality of life Patient feedback	No	Friends and Family Test

Important outcomes to commissioners?	Accident & emergency attendance	Minimum dataset outcomes, social benefits, mental health	DKA and diabetic complications Quality of life	HbA1c, reduced hospital admissions, weight and wellbeing	
Barriers/ challenges	Getting people who want to do it (difficult to engage ED service locally) Training around weight for staff Working across organisational boundaries Having enough data on outcomes for ICB ICB one of most financially challenged	Difficultly recruiting staff due to short term contracts Scaled back to include one site (staff at other site not interested)		Difficulty recruiting Diabetes Specialist Nurse One region withdrew due to capacity issues Two years short time to get from nothing to successful service.	Difficulty recruiting psychologist
Facilitators	Clinical lead with experience and contacts from London T1DE service	Discussions with existing teams Local MP involved in Parliamentary Inquiry a stakeholder		All on same systems	

Integration	<p>Integrated MDT</p> <p>Meetings with T1DE ED based service</p> <p>Follow-up appointments done in pairs</p>	<p>Integrated MDT</p> <p>Joint weekly appointments with DSN and dietitian or psychiatrist</p> <p>Remain under local ED and diabetes teams – copy and communicate with teams</p>		<p>Integrated MDT weekly and two-weekly (latter with diabetologist and psychiatrist)</p> <p>Joint assessments</p> <p>Quarterly meeting to go through lessons learnt, near misses etc.</p>	<p>Integrated MDT</p> <p>Monthly oversight meetings</p>
Education and awareness	<p>Transformation in primary care – upskill people</p>	<p>Raising awareness of T1DE in mental health teams , primary care and district nurses</p>			

DKA – diabetic ketoacidosis; ED – eating disorder; ICB – integrated care board; MH – mental health; MP – Member of Parliament; MDT – multidisciplinary team meeting; DSN – Diabetes Specialist Nurse; T1DE – Type 1 diabetes disordered eating

Appendix 2: Staff survey

Table A1: Mean scores on the NoMad questionnaire - general questions about the service (rated on a scale from 0-10)

	All services	New pilots	
	Baseline (n=26)	Baseline (n=20)	Follow-up (n=20)
	Mean (SD)	Mean (SD)	Mean (SD)
How familiar does the T1DE service feel?	5.70 (2.98)	5.05 (2.86)	6.80 (1.91)
T1DE service currently a normal part of work?	5.74 (3.50)	6.05 (3.20)	7.20 (2.31)
T1DE service will become a normal part of work?	6.93 (3.08)	7.40 (2.74)	6.70 (3.11)

SD = standard deviation

Table A2: Mean scores on the NoMAD questionnaire at baseline for all staff (n=26) and staff in new pilot services (n =20) and for staff at new pilot services at follow-up (n=20) (rated on a Likert scale from 1 to 5)

	All services	New pilots	
	Mean score baseline	Mean score baseline (n=20)	Mean score follow-up (n=20)
Coherence			
I can see how the T1DE service differs from usual ways of working	4.44	4.37	4.32
Staff in this organisation have a shared understanding of the purpose of the T1DE service	4.04	4.05	4.00
I understand how the T1DE service affects the nature of my work	4.22	4.12	4.16
I can see the potential value of the T1DE service	4.81	4.75	4.65
Cognitive participation			
There are key people who drive the T1DE service forward and get others involved	4.54	4.53	4.30
I believe that participating in the T1DE service is a legitimate part of my role	4.75	4.83	4.32
I'm open to working with colleagues in new ways to deliver the T1DE service	4.88	4.83	4.53
I will continue to support the T1DE service	4.65	4.70	4.58
Collective Action			
I can easily integrate the T1DE service into my existing work	3.57	3.88	3.83
The T1DE service disrupts working relationships*	4.08	4.05	4.32
I have confidence in other people's ability to deliver the T1DE service	4.19	4.50	4.10
Work is assigned to those with skills appropriate to the T1DE service	4.08	4.21	4.25
Sufficient training is provided to enable staff to implement the T1DE service	3.69	3.80	3.80
Sufficient resources are available to support the T1DE service	3.08	3.60	3.65
Management adequately supports the T1DE service	3.69	4.10	3.75
Reflexive monitoring			
I am aware of reports about the impact of the T1DE service	4.20	4.05	3.65

The staff agree that the T1DE service is worthwhile	4.60	4.58	4.45
I value the impact that the T1DE service has had on my work	4.52	4.47	4.42
Feedback about the T1DE service can be used to improve it in the future	4.68	4.68	4.55
I can modify how I work with the T1DE service	4.50	4.44	3.83

Scores range from 1-5, where 1 = strongly disagreed to 5 = strongly agreed; higher scores represent higher agreement with a particular statement. *Scores on the statement 'The T1DE service disrupts working relationships' were reverse coded.

Table A3: Mean scores on the Acceptability of Intervention Measure (AIM), Intervention Appropriateness Measure (IAM), and Feasibility of Intervention Measure (rated on a Likert scale from 1 to 5)

	All services	New pilots	
	Mean score baseline (n=26)	Mean score baseline (n=20)	Mean score follow-up (n=20)
Acceptability of T1DE			
The T1DE service meets with my approval	4.15	4.05	4.20
The T1DE service is appealing to me	4.38	4.35	4.40
I like the T1DE service	4.35	4.30	4.50
I welcome the T1DE service	4.54	4.50	4.65
Appropriateness of T1DE			
The T1DE service seems fitting	4.42	4.40	4.40
The T1DE service seems suitable	4.42	4.35	4.40
The T1DE service seems applicable	4.46	4.40	4.45
The T1DE service seems like a good match	4.46	4.35	4.55
Feasibility of T1DE			
The T1DE service seems implementable	4.27	4.35	4.10
The T1DE service seems possible	4.38	4.50	4.05
The T1DE service seems doable	4.42	4.50	3.90
The T1DE service seems easy to use	3.92	3.95	4.05

Scores range from 1-5, where 1 = completely disagree to 5 = completely agree; higher scores represent higher agreement with a particular statement.

Appendix 3: Economic costings

Table A3: Detailed T1DE costings by individual service (to October 2024)

List of Resources used	1			2			3			4			5		
	Unit (Grade)	(2023-2024)	(2024-Oct Only)	Unit (Grade)	(2023-2024)	(2024-Oct Only)	Unit (Grade)	(2023-2024)	(2024-Oct Only)	Unit (Grade)	(2023-2024)	(2024-Oct Only)	Unit (Grade)	(2023-2024)	(2024-Oct Only)
Pay Costs	% FTE	Y1	Y2	% FTE	Y1	Y2	% FTE	Y1	Y2 (not started yet)	% FTE	Y1	Y2 (not started yet)	% FTE	Y1	Y2 (not started yet)
Consultant Diabetologist	0.1	£13,462.19	£10,385.96	0.1		£11,399	0.4			0.2	£30,982	n/a	0.1	£12,914	£1,130
Diabetes Specialist Nurse	0.4 (B7)	£9,437.70	£15,501.50	0.5 (B7)		£19,935.16	0.7 (B7)	£8,428	£25,474.94	0.8 (B7)	£54,860	n/a	1.0 (B7)	£59,294	£5,188.25
Diabetes Dietitian	0.4 (B7)	£11,534.96	£15,501.50	1.0 (B7)		£22,908.55	0.5 (B7)		£11,301.88			n/a			
Project Manager	0.2 (B7)	£12,583.60	£7,750.75									n/a	0.4 (B7)	£23,718	£2,075.33
Admin	0.2 (B3)	£5,990.02	£3,692.85	1.0 (B4)		£15,799.67	0.4 (B3)				£31,435	n/a	0.6 (B4)	£16,802	£1,714.00
Admin - Service Co-ordinator										0.5 (B7)					
Psychiatrist				0.1		£12,386				0.25	£38,817	n/a	0.1	£12,914	£1,130
Psychotherapist										0.6 (B7)		n/a			
Psychologist	0.2 (8B)	£7,215.96	£7,617.42	0.5 (B8)		£16,088.77	0.4 (B8a)	£2,234	£15,784.52	0.5 (B-8B)	0	n/a			
Eating Disorder Dietitian										0.8 (B-8A)	£53,806	n/a	0.6 (B7)	£37,324	£3,112.92
Eating Disorder Therapist										1.0 (B7)	£0	n/a	1.0 (B7)	£55,509	£5,188.25
Mental Health Nurse	0.4 (B7)		£0.00									n/a	0.4 (B6)	£16,773	£1,467.58
Medical Consultant							0.08	£18,504	£11,444.08			n/a			
Other	0.2 (8B)	£17,318.31	£10,664.38									n/a			
Total pay costs		£77,542.74	£71,114.36		NA	£98,517.15		£29,166	£64,005.42		£209,900	£0.00		£235,248	£21,006.17
Non Pay Costs															
Venue															
Travel Cost											£500			£2,383	
IT Equipment						£1,647				3	£2,628			£1,057	
Evaluation and analysis															
Staff Training (T1DE team)		£1,098.00	£75.00								£500				
Engagement, Awareness and Educational Materials (outreach external to T1DE team)														£6,269	
Phones & Mobile Phones														£533	
Consumables										1	£339				
Communications about the service incl set up website and referral pathways															
Overheads						£24,500.00		£78,260	£25,905					£21,607	
Other														£2,706	
Total non pay costs		£1,098.00	£75.00		NA	£26,147.00		£78,260	£25,905.00		£3,967	£0.00		£34,554	£0.00
		£78,640.74	£71,189.36		£114,000	£124,664.15		£107,426	£89,910.4		£213,867	£80,991.0		£269,802	£21,006.17
Grand Total			£149,830.10			£238,664			£197,336			£294,858			£290,809
No. patients on care pathway			12			10			11			36			10
Cost per patient on care pathway			£12,485.84			£23,866.41			£17,939.67			£8,190.49			£29,080.87