Investigation report

Insulin: supporting safe self-administration for patients in the community with a mental health problem

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Before reading this report

This report considers the care of people experiencing mental health problems and includes discussion about eating disorders, self-harm, suicide and death. Some readers may find the contents distressing. Information about mental health support can be found via the NHS and charities such as Beat Eating disorders.

A note of acknowledgement

The investigation team would like to thank the many people who contributed to this report. Patients, families and staff affected by the patient safety issue shared their personal experiences with us, including intimate and traumatic situations. In particular the team would like to thank the families of Alex and Megan; the sharing of their experiences clearly demonstrates the impact of the safety issue on people.

About this report

This report is the first in a series considering the self-administration of insulin by people with diabetes mellitus in community settings. Each report will focus on specific groups of people who, due to their circumstances, may be at increased risk of harm because of the way they self-administer insulin. HSSIB are also undertaking an investigation into supporting safe administration of insulin in inpatient settings.

This report focuses on adults who live with diabetes mellitus who require insulin treatment, and who have not self-administered insulin as intended secondary to a mental health problem. While the findings of the report are around insulin and diabetes care, they may also be applicable to other physical long-term conditions that people experience. The investigation also included a focus on adults with ‘type 1 diabetes and disordered eating’. Services for children and adolescents were not within the scope of this investigation but findings may be applicable to this group.

The terminology used in this report has been chosen while acknowledging that there are differing views across organisations and groups. The report refers to ‘patients’ in line with NHS documents and people with a ‘mental health problem’ in line with Mind (2017). A glossary of terms is provided in section 6.

Executive summary

Background

This investigation report is the first in a series considering the self-administration of insulin by people with diabetes mellitus (diabetes) in community settings. It focuses on adults with a mental health problem who are known to or under the care of secondary mental health services (specialist services provided in the community), who have been harmed when they have not self-administered their prescribed insulin as intended – this is referred to as the patient safety issue in this report. People have come to harm or have died as a result of self-administering too much insulin and/or not self-administering insulin when it is needed.

Experiences of those affected

The investigation learned about the experiences of those affected by the patient safety issue by hearing from patients, families, carers and staff across primary care, mental health and specialist diabetes services. These experiences included those of Alex and Megan, shared with the investigation by their families. Alex died following self-administration of excess insulin. Megan had a diagnosis of type 1 diabetes with disordered eating and died by suicide. Both Alex and Megan experienced difficulties accessing the specialist mental health and diabetes care they needed.

The investigation

Hearing the experiences of all those affected led the investigation to examine the following in relation to the patient safety issue:

- collaboration between mental health and specialist diabetes services
- care for patients experiencing a mental health crisis
- access to insulin devices and technology.

The investigation's findings are offered to support improvements in care for people who have a co-existing mental health problem and diabetes requiring treatment with insulin. Several findings may also be applicable to how mental health and broader physical health care services are integrated around the needs of patients.

Findings

Findings related to collaboration between mental health and specialist diabetes services

- Patients with a mental health problem and diabetes (requiring treatment with insulin) in the community are not always under the care of specialist diabetes services when this would be expected in their care (for example patients with type 1 diabetes).
- Patients have been discharged from specialist diabetes services after missing one or more appointments (‘did not attend’). Patients may be discharged without consideration of their circumstances and clinical risk.
- Patients have disengaged from specialist diabetes services when adjustments have not been made for their mental health needs. Services had limited access to support from specialist mental health teams.
- Community mental health teams feel responsible for their patients’ diabetes care when they are not under the care of a specialist diabetes service. Teams have limited routes through which to access support around insulin management.
- There is variable integration of mental health and specialist diabetes services in different parts of the country. This is despite recognition of the disconnect between services and the risks to patient safety and physical health.
- Digital integration between mental health and specialist diabetes services is also variable. This has created barriers to information sharing and has contributed to patient safety incidents.
- Integrated care boards face barriers – such as resource limitations, workforce shortages and separated policy teams – to developing integrated arrangements between mental health and specialist diabetes services.
- There are unclear national plans for the long-term integration of mental health and physical health services, with limited national collaboration between relevant policy teams to address the issues.
- There continues to be no effective mechanism to allow regulatory oversight of care pathways that span different providers/organisations, such as for integrated mental health and diabetes care.
- The combination of type 1 diabetes and disordered eating (T1DE) contributes to significant patient harm. There are varying views about whether T1DE is a specific condition, and research gaps around the identification of and care for patients with T1DE.

- Long-term funding for T1DE services is at risk due to factors including their cost, highly specialist nature and concerns about limiting access to services for other people with diabetes and a mental health problem.
- People experiencing homelessness face challenges accessing the support they need for their mental health and diabetes. Limited data on the need for services influences investment, and prejudice may be a factor.

Findings related to access to insulin devices and technology

- There are no insulin pen devices designed in such a way that would prevent a patient from intentionally self-administering excess insulin.
- Limitations in data collected by manufacturers and national organisations means the patient safety issue in this investigation may not be apparent to manufacturers.
- Changes to insulin pen device design in response to patient safety issues may not be considered when the issues have arisen through use of the device outside of its intended purpose.
- Some patients may be being disadvantaged by not being considered for continuous glucose monitoring or hybrid closed loop systems due to their mental health problem.

Findings related to care for patients experiencing a mental health crisis

- Community mental health teams face barriers that prevent them from forming therapeutic relationships with patients and therefore the making of safety plans should the patient feel the urge to self-harm.
- People with a diagnosis of personality disorder face challenges accessing specialist mental health services that are able to meet their specific needs.
- Mental health teams may not fully recognise the risks of self-harm associated with access to different types of insulin. This is not consistently covered in pre-registration mental health practitioner training.
- Care planning does not always consider the safeguarding of patients who experience rapid and extreme fluctuations in their emotions and mental capacity, placing them at risk of self-harm.
- Information supportive of a patient’s safety may be withheld from their family – as a result of the patient declining sharing – without staff considering the context, and the patient's mental capacity and whether they recognise the potential benefits and risks of the decision.

HSSIB makes the following safety recommendations

Safety recommendation R/2026/073:

HSSIB recommends that NHS England/Department of Health and Social Care develops a strategy for improving collaboration between mental health teams and specialist diabetes services, that includes consideration of responsibilities for integrated working at national, regional and local levels. This is to support future integration of services that will benefit all patients with mental health and diabetes care needs, including patients who are required to self-administer insulin and patients with type 1 diabetes and disordered eating.

Safety recommendation R/2026/074:

HSSIB recommends that the National Institute for Health and Care Research, in collaboration with relevant research and policy stakeholders:

1) maps the knowledge gaps surrounding type 1 diabetes and disordered eating (including those identified in this investigation); and

2) assesses the priority and feasibility of commissioning research to help address those gaps.

This is to help develop new knowledge to inform future decisions for the delivery of safe and effective care for this group of patients.

Safety recommendation R/2026/075:

HSSIB recommends that Royal College of Psychiatrists, through collaboration with relevant stakeholders, develops a strategy that:

1) supports consistent recognition of patients with type 1 diabetes and evidence of disordered eating; and

2) identifies associated care responsibilities for providers of mental and physical health services.

This is to help improve the NHS’s recognition of patients who are affected and to support decisions around the commissioning of services.

HSSIB makes the following safety observations

Safety observation O/2026/081:

Organisations involved in the provision of undergraduate and pre-registration education and preceptorship/induction programmes can improve patient safety by ensuring that staff have knowledge of diabetes, an understanding of how and why insulin is a vital treatment for many people with diabetes, and the risks that the use and misuse of insulin can present for patients with a mental health problem.

Safety observation O/2026/082:

Organisations involved in the manufacture of insulin pen devices used by the NHS can improve patient safety by:

1) understanding where devices are being used outside of their intended purpose; and

2) exploring the potential to design devices that would reduce the risk of intentional overdose of insulin for self-harm.

HSSIB suggests safety learning for integrated care boards

HSSIB investigations include safety learning for integrated care boards where this may support the response to a patient safety issue across a geographical footprint.

Safety learning for integrated care boards ICB/2026/014:

HSSIB suggests that integrated care boards formalise collaborations between mental health and specialist diabetes services in their local systems. Through co-production with people with lived experience, this should look to include:

- care arrangements for people with a mental health problem and diabetes, particularly for those who require insulin
- routes for community mental health teams to access advice where their patients have diabetes and access to insulin
- routes for diabetes specialist teams to seek advice from mental health teams about reasonable adjustments for patients under the care of outpatient clinics
- enablement of interoperability between electronic systems to support information sharing.

Safety learning for integrated care boards ICB/2026/015:

HSSIB suggests that integrated care boards develop data-driven approaches for the understanding of local need to inform decisions about services for patients who have been identified as marginalised in this investigation. These are patients with:

1) co-existing mental health and long-term physical health needs (diabetes), including those with a diagnosed personality disorder and/or experiencing homelessness; and

2) type 1 diabetes and disordered eating.

Local-level learning

HSSIB investigations include local-level learning where this may help providers/organisations respond to a patient safety issue at the local level.

For organisations providing mental health and/or specialist diabetes services:

- Does your organisation have a specific job role with responsibility for cross-organisational care pathways to ensure the holistic needs of patients, including those with mental health problems and diabetes, are met?

- How does your organisation ensure information about patients is available to other providers of care when required, for example to mental health teams about a patient’s diabetes care?
- How does your organisation ensure staff are aware of their responsibilities to report incidents associated with diabetes medication and technology, including to manufacturers and the Medicines and Healthcare products Regulatory Agency?
- Does your organisation have a process for identifying and appropriately supporting patients with type 1 diabetes who also have evidence of disordered eating?

For organisations providing specialist diabetes services:

- How does your organisation ensure patients with a mental health problem are not being discharged from clinics following a ‘did not attend’ without consideration of their circumstances and risks to their safety?
- Do your staff recognise the need to make reasonable adjustments for patients, including for those with a mental health problem, to support access to care?
- Does your organisation have a liaison psychiatry service that supports inpatient and outpatient services for people with a mental health problem?
- Does your organisation have clear routes via which services can seek support from specialists in mental health if a patient is found to be experiencing a crisis?
- How does your organisation identify patients who have had recurrent admissions with diabetic ketoacidosis or hypoglycaemia, and support staff to consider whether these patient require input from mental health services?
- How does your organisation ensure patients with a mental health problem, who meet the criteria for diabetes technology, are receiving support to access it and are not being discriminated against because of their mental health problem?

For organisations providing mental health services:

- How does your organisation ensure staff working in the community have access to advice about a patient's physical health, including specialist advice for conditions such as diabetes requiring treatment with insulin?
- How does your organisation keep staff up-to-date about the different types of insulin used in the NHS and their onset times to ensure this is considered as part of assessment of a patient's risk of self-harm?
- How does your organisation enable staff to work therapeutically with patients to support them to develop safety plans which include consideration of the risks associated with insulin?
- How does your organisation support multidisciplinary discussion in discharge planning that recognises the circumstances a patient is being discharged into to ensure they are appropriate for their mental and physical health needs?
- How does your organisation support staff to make assessments under the Mental Capacity Act, with particular consideration of whether the patient can use and weigh information as part of their decision making?
- Does your organisation provide services that effectively meet the needs of people with rapidly fluctuating and extreme emotions, and that consider how best to support these patients when they are unable to make decisions to keep themselves safe?
- Do your staff recognise the importance of family involvement in patient care, and where the patient refuses this, do staff ensure the reasons for refusal and the potential ramifications are explored and it is appropriately revisited over time?
- How does your organisation support staff to not make assumptions about patients based on their circumstances and characteristics?

1. Background and context

This report is the first in a series considering the self-administration of insulin by people with diabetes mellitus (diabetes) in community settings. This report focuses on adults who are experiencing a mental health problem who are known to or under the care of secondary care (specialist) mental health teams.

HSSIB identified incidents where people with diabetes and a mental health problem had been harmed when they had intentionally not used their insulin as prescribed (the patient safety issue of focus). The incidents included where patients had died or experienced life-changing harm.

This section provides background information about topics discussed in the investigation.

1.1 Diabetes mellitus and insulin

1.1.1 Diabetes mellitus (commonly referred to as ‘diabetes’) is a condition where the level of sugar in a person’s blood is too high. The body normally controls blood sugar levels through the production of the hormone insulin by the pancreas but this ability is lost in diabetes. Around 4.3 million people in the UK have diabetes (Diabetes UK, n.d.a) and ‘managing the growing incidence of diabetes in England is set to be one of the major clinical challenges of the 21st century’ (NHS England, n.d.).

1.1.2 Around 8% of people with diabetes have type 1 and 90% have type 2. In type 1 diabetes, the pancreas does not produce insulin and so people will need lifelong insulin therapy. In type 2 diabetes, the body does not produce enough insulin or the body's cells become resistant to insulin; the person may need insulin therapy if appropriate (Diabetes UK, n.d.b). There are also other types of diabetes, such as type 3c which can develop following damage to a person’s pancreas.

1.1.3 A person’s health can be harmed if their blood sugar levels are too high or too low. High levels (hyperglycaemia) – causes of which include concurrent illness – can lead to life-threatening complications such as diabetic ketoacidosis in which acids accumulate in the blood. Low levels (hypoglycaemia) – causes of which include taking too much medication or missing food – can in severe cases result in loss of consciousness and death. In the longer term, high blood sugar levels can cause damage to blood vessels and nerves with resulting complications affecting different parts of the body, such as the eyes and kidneys. People are also at increased risk of conditions such as heart attack and stroke.

1.1.4 When managing diabetes, the aim is to manage blood sugar levels within a target range. Sugar levels are measured by sampling blood via a finger-prick test, a blood test or a continuous glucose monitor (CGM). A CGM can provide intermittent or real-time readings of a person’s sugar level. The National Institute for Health and Care Excellence (NICE) (2022a; 2022b; 2023a) recommends that all people with type 1 diabetes and some people with type 2 should have access to a CGM.

1.1.5 To monitor blood sugar levels over time, a person’s glycated haemoglobin (HbA1c) is measured (Diabetes UK, n.d.c). HbA1c measures the amount of sugar sticking to red-blood cells and provides an indication of average levels from the past 2 to 3 months. For someone with diabetes, NICE (2022a; 2022b) provides guidance on target HbA1c. A person’s target HbA1c should be individualised to ensure their circumstances are considered including their risk of hypoglycaemia.

Insulin therapy

1.1.6 Insulin can be administered by subcutaneous injection or pump to help people manage their blood sugar levels. There are different types of insulin with different onset times (how long it takes to take effect) and duration of action. For example, a rapid-acting insulin may onset in 5 to 15 minutes and last 2 to 5 hours, while a basal (background/long-acting) insulin may onset in 2 hours and last 18 to 42 hours (Diabetes Specialist Nurse Forum UK, 2024).

1.1.7 All people with type 1 diabetes need insulin to replace what is not produced by their pancreas. For people with type 1 diabetes using insulin injections, NICE (2022a) recommends using a basal insulin and then rapid-acting insulin before meals. Some people living with type 2 diabetes also require insulin if other medications have not enabled adequate control of blood sugar levels.

1.1.8 Insulin can also be administered as a continuous subcutaneous infusion via a stand-alone insulin pump or hybrid closed loop system. Hybrid closed loop systems involve a pump and CGM ‘talking to each other’ to automatically adjust the insulin dose (Diabetes UK, 2025a). NICE (2022a; 2023b) recommends hybrid closed loop systems as an option for certain people.

1.2 Safe self-administration of insulin

1.2.1 Self-administration of insulin is where people inject the medication themselves; it may also include use of a pump (see 1.1.6). Diabetes UK (2025b) provides resources on how to use an insulin pen device and steps include: choosing where to inject; attaching a needle to the pen and priming the device; dialling up the dose; injecting the insulin and counting to 10; and safely disposing of used equipment.

Considerations for safe self-administration of insulin

1.2.2 Insulin is a time-critical and high-risk medication – it should not be omitted without a valid clinical or safety reason, and can have serious side effects (see 1.1.3). The vast majority of the administration of insulin in community settings is done by the patient and it requires certain knowledge and skills to ensure it is done safely.

1.2.3 Considerations for safe self-administration of insulin are multiple and include the following (Diabetes UK, 2023):

- **Insulin** – there are different types of insulin (see 1.1.6). Some have similar names but may differ in type and strength. The person should understand the types they are prescribed, how quickly they act and how to prepare them. Insulin requires appropriate storage and unopened supplies should be stored in a refrigerator.
- **Dose** – insulin doses will be tailored to each person and how much they need will depend on factors such as their weight, the type of diabetes they have and what they are eating. The person should understand their doses and how doses may need to be adjusted depending on their blood sugar levels.
- **Time** – insulin may need to be taken at different times. Some is taken around a mealtime and some may need to be taken at the same time each day such as bedtime. The person should understand when they need to take their insulin.
- **Device** – the type of administration device used will depend on the type of insulin. The person should understand how to prepare, use and store the device. The person also needs to understand what other kit is needed to administer their insulin and measure blood sugar levels, and ensure they have enough supplies.
- **Technique** – administering insulin in the right way ensures it is effective. The person needs to understand the technique for administering insulin and should vary the administration site to avoid the development of fatty lumps (lipohypertrophy) that may affect insulin absorption. Sites for injection also need to be kept clean to avoid infections.
- **Complications** – a person who self-administers insulin needs to understand the potential for complications, how to identify them and how to manage or seek help for them. This includes insulin dose adjustment for the management of hyperglycaemia and hypoglycaemia, as well as during illness.

1.2.4 A diabetes diagnosis has lifelong implications. The considerations associated with self-administration of insulin and self-care are significant. Whether someone is able to effectively self-care will vary depending on their circumstances, for example their age, support network, health literacy, cognitive functioning and mental health (Alexandre et al, 2021).

1.3 Mental health problems

1.3.1 Around a quarter of the population of England will experience a mental health problem each year (Mind, 2017). A mental health problem is a change to a person's mental wellbeing that impairs their ability to function as they would do normally. Severe mental health problems include psychosis, bipolar affective disorder, complex emotional needs/personality disorder, eating disorders and severe depression (NHS England, 2024a).

1.3.2 Mental health problems can lead to distressing thoughts including of self-harm. A 'crisis' is where a person may feel at breaking point, leading to thoughts of self-harm (Mind, n.d.). For some people, self-harm is a way to release overwhelming emotion (Royal College of Psychiatrists, 2020a). However, serious and repeated self-harm is strongly associated with suicide (Witt et al, 2019). People living with long-term conditions, such as diabetes, are at increased risk of self-harm and dying by suicide (Nafilyan et al, 2023).

1.3.3 Mental health services are provided across primary (for example via general practice), secondary and tertiary (for example specialist eating disorder services) care. Secondary care services are specialist and in the community include mental health teams, crisis teams and home treatment teams.

Mental health and diabetes

1.3.4 The physical health of people with a severe mental health problem is worse than that of the general population (National Institute for Health and Care Research, 2023a; Public Health England, 2018). Patients in this group have shortened life expectancy, higher levels of obesity contributed to by factors such as medications, and higher rates of behaviours such as smoking. Some long-term conditions, including diabetes, are more common in people with a severe mental health problem (Ward and Druss, 2015).

1.3.5 A person's diabetes can influence their mental health, and their mental health has the potential to influence how they self-care. It is known that people with diabetes and a mental health problem have poorer health compared to people with diabetes alone (Vinogradova et al, 2010). People who self-harm and who have diabetes with access to insulin may use their medication to self-harm – this may be by intentionally taking too much or not enough insulin. Self-harm can also include where people may stop taking their insulin.

1.3.6 People with type 1 diabetes who develop disordered eating behaviours or restrict the amount of insulin they take – in order to reduce body weight or avoid weight gain – are described to have ‘type 1 diabetes and disordered eating’ (T1DE) (Breakthrough T1D, 2024). The term T1DE also includes people with type 1 diabetes and an eating disorder. Research suggests that people with T1DE face a ‘three-fold’ higher mortality rate than people with type 1 diabetes who do not restrict insulin (Goebel-Fabbri et al, 2008). The Royal College of Psychiatrists (2022a) has published an annexe to their medical emergencies in eating disorders guidance that focuses on T1DE with proposed criteria and recommendations for assessment and treatment.

1.3.7 Diabetes can also affect a person’s mental health. Diabetes distress (also known as diabetes-specific distress or diabetes-related distress) is the emotional response to living with diabetes, the burden of relentless daily self-management and the prospect of long-term complications. Distress may increase as a person needs more intensive treatment – such as with insulin – and when they are experiencing a mental health problem (Priesterroth et al, 2025). Depression is also more common in people living with diabetes compared to the general population (Moulton et al, 2015).

1.3.8 The need to improve access to physical health services for people with a mental health problem has been clearly stated since 2012. This was when the concept of ‘parity of esteem’ – the valuing of mental health equally with physical health – was included in the Health and Social Care Act 2012. Since 2012, reports have consistently highlighted a treatment gap, with individuals with mental health problems receiving less preventative care and treatment for long-term physical health conditions (Health Services Safety Investigations Body, 2025a).

2. Experiences of those affected

This section describes the patient safety issue through the perspectives of those affected. It includes the experiences of Alex and Megan which were shared with the investigation by their parents. These experiences were not investigated by HSSIB but have been shared to demonstrate several challenges faced by patients when seeking care for a mental health problem and insulin treated diabetes.

2.1 Alex’s experience

2.1.1 Alex was 26 at the time of her death. She was described by her family as “incredibly bright and articulate”. She wanted to “look after others” but could not cope with her own “chaos”. That chaos had been with her since early life and caused extreme fluctuations in her emotions where things were “all brilliant or all terrible”.

2.1.2 Alex was diagnosed with type 1 diabetes at the age of 14 and she struggled to manage her condition alongside her complex emotions. Over the years, her emotions influenced her management of her blood sugar levels and she had periods where she did not take her insulin or took too much. It was discussed whether Alex would benefit from continuous glucose monitoring and an insulin pump but this did not happen because of the “poor control” of her blood sugar levels and in light of her emotional difficulties.

2.1.3 Alex was diagnosed with an emotionally unstable personality disorder (EUPD). Following the diagnosis, Alex was offered some support but her family described that this did not meet her needs. Over a 6-month period Alex self-harmed using insulin and was admitted to hospital 4 times. These admissions were to acute hospitals with a focus on Alex’s physical health and did not provide the support she needed for her mental health.

2.1.4 In the month prior to her death, Alex attended an emergency department after self-administering excess insulin. Following treatment, she was informally admitted to an acute mental health ward. The admission did not provide the support Alex had hoped for and as the point of discharge approached she expressed feelings of ‘hopelessness’. Alex also told staff that she would not be able to stop herself from further self-harm as she lost control when her emotions fluctuated to the extreme. An assessment by a community mental health team also suggested she was not ready for discharge.

2.1.5 At a multidisciplinary team discussion in hospital it was agreed that Alex would be discharged with follow-up from the community crisis team. At discharge, it was noted that Alex was at ongoing risk of self-harm, but that she had mental capacity to manage her insulin. Alex had also identified herself as homeless and, through contact with housing services, a hotel was found.

2.1.6 The community team saw Alex several times after discharge from hospital. Alex told the team of her ongoing concerns that she would self-harm on impulse as she would not be able to control herself and had easy access to insulin. She was not eating well and felt isolated in the hotel. She had also been unable to go to a GP appointment to review her diabetes because she could not get there.

2.1.7 Four days after discharge, Alex was found unresponsive in the hotel room by the community team. Nearby were empty medication packets, insulin pens and a bottle of alcohol. Attempts to resuscitate Alex were unsuccessful.

Issues shared by Alex's family

2.1.8 Alex's family described a lack of support for her mental health and diabetes needs. There were no services available to her that brought specialist mental health and diabetes services together. Collaborative care planning did not occur and questions related to Alex's access to insulin, support for her safety, and the potential benefits of other diabetes technology were not considered.

2.1.9 In terms of Alex's mental health, her family described an absence of services for her complex and fluctuating emotions. They also shared that Alex felt her needs were dismissed by services in light of her articulate nature and privileged background. This influenced her to identify as homeless in an attempt to demonstrate her vulnerability.

2.1.10 Alex's family and staff raised concerns about the planning and speed of her discharge from hospital. Alex was continuing to state that she was unable to prevent self-harm and she was discharged to an isolated location away from support services, her family and amenities. The discharge did not involve input from Alex's family, housing services or community mental health teams, and the hospital team involved in Alex's discharge did not know her discharge address and therefore were unaware of the hotel's circumstances.

2.1.11 Determination that Alex had mental capacity in relation to her insulin management was also questioned by her family. They described that Alex had a clear pattern of self-harm with insulin when she lost the ability to control her actions. While she may have had capacity to decide not to self-harm with insulin at the point she was assessed, this did not proactively safeguard Alex for when she would lose capacity. Alex's family further described how information that may have helped with Alex's safety and support was not communicated to them due to Alex declining the sharing of information; Alex declined on one occasion and it was unclear whether this decision was explored or revisited.

2.1.12 Staff involved in Alex’s care described the options they explored to try to restrict her access to insulin to reduce the risk of self-harm. Alex needed access to insulin for the management of her diabetes, but was also at risk of taking excess on impulse. Options explored included different pen devices, smaller volume pens, and whether administration could be organised via a GP or community nursing team. No alternatives were found and Alex was discharged with a single pen of each of her insulin medications. Alex attempted to protect herself by moving her medication out of sight.

2.2 Megan's experience

2.2.1 Megan was 27 at the time of her death. She was described as “very bright” and from an early age had displayed “a strong sense of wrong and right”. Megan became a teacher and outwardly she presented as someone who was doing well in life.

2.2.2 Megan was diagnosed with type 1 diabetes at the age of 16 after being admitted to hospital unwell and with extreme weight loss. She was treated for diabetic ketoacidosis (DKA) (see 1.1.3) and experienced significant swelling and weight gain; the reasons for this were not explained to her. Before her diabetes diagnosis, Megan had exhibited patterns of disordered eating – that is, abnormal eating behaviours.

2.2.3 Over the following years, Megan was described as having a “poor relationship” with her insulin and there was ongoing evidence of disordered eating. Megan recognised an association between her insulin use and her weight. Around 10 years after her diabetes diagnosis, it was suggested that she may have a condition called “diabulimia” (a previously used term for type 1 diabetes with disordered eating or T1DE).

2.2.4 Megan received care for her diabetes through a specialist clinic. However, she expressed feelings that she felt ‘judged’ by staff and unsupported; this made her reluctant to engage with further appointments. The diabetes clinic recognised that Megan had disordered eating and so referred her for eating disorder care at a separate eating disorder community clinic.

2.2.5 Later, Megan was detained under the Mental Health Act 1983 after self-administering excess insulin. While an inpatient on an acute mental health ward, Megan shared that she felt unsafe because the ward did ‘not know how to cope with [my] diabetes’; she did not have access to specialist diabetes care on the ward.

Despite concerns for her safety, Megan was discharged to await an inpatient place at an eating disorder unit. During this time Megan was admitted to hospital for emergency treatment for episodes of DKA.

2.2.6 During her 3 month stay at the eating disorder unit, Megan's physical condition stabilised but her suicidal ideation did not improve; this resulted in a further episode of self-administering excess insulin. The team caring for Megan deemed that she had capacity to make decisions and she was later discharged back to community care.

2.2.7 After discharge, Megan's physical and mental health deteriorated and she required several further admissions to hospital with DKA. Later the same year Megan died by suicide. She had left a letter to her family describing her experiences and expressing that she did not feel she had received the care she needed from mental and physical health services. Her cause of death was suicide in the context of a diagnosis of personality disorder and T1DE.

Issues shared by Megan's family

2.2.8 Megan's family told the investigation that she had never received a formal diagnosis of T1DE. They described a lack of an accepted definition of the condition and an absence of pathways for care that they knew had also impacted other patients. They described "siloed" treatment models and no joint working between specialist mental (eating disorder) and physical (diabetes) health services. There were no proactive provisions put in place to support Megan to administer her insulin safely and consistently.

2.2.9 Megan's family also shared concerns that her risk of self-harm was under-recognised by the healthcare teams caring for her. This was despite evidence that she was not managing her condition safely and was repeatedly engaging in life-threatening behaviours. They described that Megan had decided that she wanted to be out of hospital and had made the decision to end her life. She knew to "say the right things" during assessments by mental health teams and used this to facilitate her discharge.

2.2.10 At the point of discharge from hospital, a mental capacity assessment found Megan to "have capacity to make decisions". Her family questioned whether Megan's bright and articulate persona masked the severity of her internal struggles and whether she was able to care for herself. They shared their perceptions that the assessment did not recognise that Megan's decision making may be impaired by diabetes and disordered eating. They also raised concerns that the assessment was undertaken by staff unfamiliar with T1DE.

2.2.11 Megan’s family also questioned why information was not shared with them by the hospital that would have potentially helped them to support and safeguard Megan. Information was not shared as Megan had declined and was deemed to have capacity to make this decision. Megan’s family believed that she required continuous support and that her safety was not prioritised.

2.3 Further experiences

2.3.1 As well as meeting Alex's and Megan’s families, the investigation heard the perspectives of other patients, families and staff. This included hearing about a specific patient who repeatedly self-harmed with insulin and for whom the community mental health team had exhausted all available support options. The team expressed concerns that this patient would, at some point, die as a result of self-harm. During the course of the investigation this patient died following self-administration of excess insulin.

2.3.2 Patients described the emotional burden of diabetes and the influence this had on their mental health and how they self-administered insulin. Several spoke about admissions to hospital after not self-administering insulin as prescribed. Several patients had also developed long-term complications from high blood sugar levels, including vision loss.

2.3.3 Patients and their families described difficulties accessing specialist diabetes care when someone had a mental health problem. Patients had disengaged from services or had been discharged after not attending an appointment. Patients also variably engaged with primary care services including their GPs. Patients therefore relied on community mental health staff, with whom they had built a relationship, for diabetes and physical healthcare support.

2.3.4 From a staff perspective, a patient experiencing a mental health problem with access to insulin was described as a “huge red flag”. Several staff had known patients who had died following self-harm with insulin. They told the investigation they were “scared” and often “helpless to do anything”.

2.3.5 Some community mental health staff also felt that they had been made responsible for the mental and physical health needs of their patients, but had limited options to meet those needs. Where incidents had occurred, staff described evidence of moral injury (psychological harm caused when a person is exposed to situations that conflict with their values and beliefs) and distress caused by subsequent investigatory and coronial processes.

2.4 Summary

2.4.1 Patients are coming to harm from misuse of a medication that those prescribed may not be able to live without. The safety of these patients relies on delivery of care that meets their mental and physical health needs in a holistic way. The experiences of those affected demonstrate factors that contribute to variability in how care is delivered, including the level of collaboration between mental health and specialist diabetes services; the ability of mental health services to therapeutically meet a person’s needs; and options to restrict access to insulin to reduce the potential for self-harm.

3. Analysis and findings – collaboration between mental health and diabetes services

Sections 3 and 4 of this report describe the investigation’s national examination of the factors identified in section 2. With a focus on adults with diabetes and a mental health problem in the community, the following areas were explored in relation to their role in the safe self-administration of insulin:

- collaboration between mental health and specialist diabetes services (section 3)
- therapeutic care for patients experiencing a mental health crisis (section 4)
- access to insulin and the risk of self-harm (section 4).

The investigation was told that the “system is stacked against people with type 1 diabetes and mental illness”. Those affected described situations representing a lack of collaboration between services, such as in Alex's and Megan’s care. This meant patient needs were not met in a “joined-up” way. To examine collaboration the investigation considered:

- access to specialist diabetes services for expert insulin management
- integration between mental health and diabetes services in community settings
- services for people with diabetes and specific needs
- barriers to information sharing between services.

3.1 Access to specialist diabetes services

3.1.1 Community mental health teams told the investigation about patients who needed support from specialist diabetes services, particularly those with type 1 diabetes, but who did not have that support. They described barriers to accessing specialist care and said that some patients who were previously “under” a specialist team were no longer receiving support. The investigation met patients who shared why services were no longer available to them:

- **Disengagement** – patients described feeling “judged” by services that took a “finger-wagging” approach and used “negative language” about how they managed their diabetes without understanding their circumstances.
- **Assumptions** – patients described that services made assumptions that the difficulties they faced with their diabetes was due to their mental health problem. Mental health teams described this as “diagnostic overshadowing”.
- **Discharge** – patients described being discharged after not attending appointments. Some were discharged after one episode of not attending.

3.1.2 Mental health teams shared concerns that specialist diabetes services did not make “reasonable adjustments” for patients – that is, changes to prevent someone being disadvantaged by a disability – and that “stigmatisation” because of a mental health problem was an issue. They described a need to ask “why” a patient may not attend an appointment – for example, the patient may fear leaving home. The need for a “flexible” approach to care was described but that this did not align with the current model of healthcare.

3.1.3 The investigation also heard from diabetes specialist teams about barriers to providing care. They acknowledged that sometimes the need for reasonable adjustments were not identified, but that staff were not mental health experts and had limited access to support from mental health teams. Staff also described a fear of asking patients about their mental health or “triggering challenging behaviours” because they did not know how to respond. Regarding discharging patients after a non-attendance, this was heard across several organisations to be “trust policy” due to waiting lists and missed appointments.

3.1.4 Community mental health teams told the investigation that disengagement and discharge from specialist diabetes services meant those patients had no specialist oversight of their insulin management. In these situations, it was heard that a patient’s care is “passed back to their GP” (see 3.1.5), despite some having “labile” blood sugar levels, complications of diabetes and complex insulin regimens. Because of variable engagement between patients and their GPs, mental health teams felt they had become “responsible for a person’s insulin” because no one else was, with limited routes to get support.

3.1.5 The investigation explored routes for support for community mental health teams when seeking advice about a patient with diabetes (requiring treatment with insulin). Teams acknowledged that there may be support but they did not know about it. Options for support varied across the country, and included:

- **The patient's GP** – commonly heard to be the "only" route. GPs told the investigation they were often not experts in insulin management, patients may disengage from their care, and they had limited capacity to outreach.
- **Community diabetes specialist nurses** – in some areas a specialist nurse could be accessed through a community trust or via the patient's general practice. This varied geographically depending on setup and commissioning, and because of a shortage of specialist staff to recruit to these roles. In some areas teams were not aware of any community diabetes support.
- **Inpatient physical health practitioners** – in several mental health trusts there was a physical healthcare team for inpatients. Teams were able to provide "ad hoc" advice to community teams and sometimes delivered education. These teams commonly had no specialism in diabetes.
- **Hospital specialist diabetes services** – mental health teams described "begging" for help from a local acute hospital's diabetes team. Formalised service agreements were not seen to be in place for collaboration between trusts. Some teams described being "lucky" and having informal relationships where they knew someone they could contact for advice.

3.1.6 The investigation also explored routes for diabetes specialist teams to seek advice about a patient with a mental health problem. Access to psychological services was described but also difficulties accessing specific mental health support. The Royal College of Psychiatrists (2013; 2019) has previously recommended that hospitals have a liaison psychiatric service which includes provision for outpatient services and specialist teams. The College described this provision as 'inconsistent' and shared a 2024/25 survey of liaison psychiatry in England. The survey showed that all acute hospitals with a type 1 emergency department (ED) had a liaison psychiatry department for inpatients/ED but only 30% provided some form of outpatient service.

3.1.7 The investigation found that there is a group of patients in the community under the care of secondary mental health services and with diabetes (who self-administer insulin), who have no specialist diabetes oversight and support for safe self-administration of insulin. Specialist services are not consistently available to these patients and routes to gain advice are limited routes. These findings have contributed to the local-level learning in 5.3.

3.1.8 The investigation also explored patient disengagement from specialist services with the Equality and Human Rights Commission (EHRC). The EHRC (2018) described that it is the duty of a public service to anticipate reasonable adjustments for someone experiencing a physical or mental disability and ensure they are provided on an ongoing basis. This is so the person has equal access to services as someone without a disability and the same level of care. A service needs to consider what can be done to reduce potential disengagement with input from people with lived experience.

Patients who do not attend appointments

3.1.9 One family told the investigation that a patient not attending a clinic appointment should be considered a ‘red flag’ not ‘disinterest’. In response to hearing that patients had been discharged when they ‘did not attend’ (DNA) specialist diabetes appointments, the investigation reviewed expectations placed on organisations for managing DNAs. The NHS Standard Contract (2025b) requires provider organisations to have a ‘local access policy’ that includes management of DNAs. The Contract states that:

- ‘… any decisions to discharge patients after non-attendance are made by clinicians in the light of the circumstances of individual Service Users …’
- ‘… blanket policies which require automatic discharge to the GP following a non-attendance are avoided …’.

3.1.10 The investigation reviewed local access policies and saw several stating that at least two appointments should be offered before considering discharge. No policies were seen to include automatic discharge after a single DNA, but the investigation heard, and other publications suggest, that this sometimes happens (Pulse, 2019). Policies included the need for consideration of clinical risk before discharge and to make efforts to contact the patient and the referring clinician. The investigation also noted that individual services within a provider may implement their own procedures for managing patient DNAs that may not align with the provider’s overarching policy.

3.1.11 The impetus for a provider to reduce DNAs was heard to be due to long waiting lists and high demand. NHS England (2023) has encouraged a reduction in DNAs in outpatient services. NHS England (2023) has also highlighted the importance that any decision to discharge a patient from outpatient services after a DNA must include clinical input, recognise safeguarding risks to vulnerable patients, and ensure that it does not lead to health inequalities. The EHRC told the investigation that an organisation must consider the equality impact of their policies to ensure they do not disadvantage people with a protected characteristic, which includes a mental disability. The EHRC (2024) have produced guidance to help organisations consider equality in policy making.

3.1.12 The investigation found that patients with a mental health problem may be being discharged from specialist diabetes services without full consideration of their circumstances by the provider organisation. Factors contributing to this include those relating to making reasonable adjustments (see 3.1.2) and pressures to reduce waiting lists (see 3.1.11). The circumstances of the patient group in this investigation mean they do not have equitable access to specialist care; as a result they may not have support to safely self-administer insulin and minimise the risks of complications. This finding has contributed to the local-level learning in 5.3.

Access to specialist diabetes support in the community

3.1.13 National organisations described variable access to community diabetes services in general, not just for people with a mental health problem. The investigation did not identify national work around improving community diabetes service provision across England. The Getting It Right First Time (GIRFT) programme – an NHS England programme to improve the care of patients by different services – told the investigation that its diabetes work had mainly focused on inpatient care and technology. GIRFT was keen to broaden its work into the community but had limited resource to do this.

3.1.14 The investigation did observe examples where community mental health teams had routes to obtain specialist diabetes and insulin advice. In one location, the mental health trust’s inpatient lead for physical health was a diabetes specialist nurse. This role was not intended to be a diabetes-specific role but the trust recognised it was fortunate to have someone with this specialism. The nurse advised community teams and had informal communication routes with the local acute hospital’s specialist diabetes team.

3.1.15 Mental health teams also suggested the potential benefits of collaborative ‘assertive outreach’ – that is, an intensive support offer that engages patients and adapts to their needs (NHS England, 2025b). They told the investigation that this approach was recognised in community mental health but could have a role in supporting physical health needs such as diabetes in the community, particularly where patients do not engage with traditional care models. It was suggested that specialist diabetes services could contribute to this approach through collaboration with mental health teams, bringing the mental health practitioner and diabetes specialist to the patient.

3.2 Integration between mental health and diabetes services

3.2.1 The investigation was told that the lack of access to specialist diabetes services was an example of the “disconnect” between mental and physical health services. This disconnect is “long standing” and continues to contribute to patient harm despite national publications having called for improvements since 2012 (see 1.3.8). HSSIB (2025a) has previously seen this disconnect in its investigations, as have other authors (for example The King's Fund, 2016).

3.2.2 Specific to diabetes care, the investigation was told about variation in services for people with a mental health problem. While “pockets” of good practice exist (see 3.2.5), the investigation identified factors influencing this variation:

- **Beliefs** – that the mind and body are distinct and separate (mind-body dualism) have influenced the historical set up of services and visibility of mental versus physical conditions (Ismail et al, 2024a).
- **History** – mental and physical health services are traditionally separate organisations with separate purposes, funding and leadership. A lack of ‘parity of esteem’ has been recognised for several years (see 1.3.8).
- **Need** – allocation of funding for services depends on integrated care board (ICB) commissioning. Physical health in the mental health setting may not be a priority. Limited data to demonstrate the need may limit funding allocation.
- **Responsibility** – mental health teams may not believe physical health to be their responsibility, and physical health teams may not believe mental health to be theirs. Separate training pathways (for example for nursing) contribute to knowledge, skill and belief differences.
- **Oversight** – while there has been recognition of the need for integration, there has been limited oversight to ensure this has happened. A lack of cross-provider accountability and limited support from ICBs were described.

3.2.3 The investigation observed that, where integrated mental health and specialist diabetes services did not exist, patients did not receive multidisciplinary care that recognised the interacting nature of their conditions. Without collaboration, patients were being cared for by mental health practitioners who were unfamiliar with the complexities of diagnoses such as diabetes, some of whom believed that they “don’t do physical health”. At a point where a multidisciplinary team (MDT) (physical and mental health) approach was identified as needed for a patient, organising this was a “nightmare” because of a lack of pre-existing arrangements.

3.2.4 The investigation found limited evidence of integrated approaches to the mental and physical health care of people with diabetes who self-administer insulin; this has also been highlighted by others (for example Ismail et al, 2024a). This has contributed to harm where patients have not been supported to safely self-administer their insulin. Multidisciplinary care was not organised around the patient, instead services acted independently.

Integrating mental health and specialist diabetes services

3.2.5 The investigation observed examples, in different parts of the country, where organisations had looked to better integrate mental health and specialist diabetes services. These included those described later in relation to type 1 diabetes and disordered eating (T1DE, see 3.3.2) and:

- A community service that had been set up following identification of the need. Local data had been scrutinised which had helped secure funding. The service had shown positive patient outcomes but had limited capacity so could only focus on those having the greatest difficulty managing their diabetes. The service focused on patients with type 2 diabetes, with the rationale that patients with type 1 diabetes should be under the specialist care (see 3.1.3).
- Another trust had embedded mental health support within the local diabetes service. Patients admitted with diabetic ketoacidosis (DKA) and other diabetes-related issues were highlighted to the team via the ED. The service focused on good mental health care and diabetes support, with inpatient review and regular outpatient follow-up.

3.2.6 The investigation also heard about historical examples of integration that had lost funding. Several services had been “too expensive” with high rates of patient DNAs (see 3.1.9) and lack of evidenced impact; these factors limited willingness for long-term investment. Concerns were shared that the NHS’s approach to funding of short-term pilot projects limits the ability of those projects to show their longer-term benefits; this then impacts on the continuation of funding. The NHS’s approach was also described as “short sighted” because it does not consider the wider patient and economic benefits of interventions such as reducing attendances at EDs.

3.2.7 The investigation met with the Royal College of Psychiatrists to hear about its work improving the physical health of people with a mental health problem. The College is preparing a position statement to support accessibility for all populations to physical health pathways. Specific to diabetes, the investigation heard that embedding mental health support and trauma-informed approaches within specialist diabetes services had the potential to improve accessibility for people with a mental health problem and created opportunities to meet a patient’s multiple complex needs.

3.2.8 The investigation also engaged with other national organisations to explore strategy and commissioning plans for integrating mental health and specialist diabetes services. Diabetes UK shared the outputs of a working group they had conducted with NHS England to develop a model for mental health care in diabetes pathways and diabetes care in mental health pathways (Sarchar et al, 2022). Other stakeholders did not identify specific plans to the investigation for addressing the integration issues other than pilot work underway at the time for T1DE (see 3.3.5). The national focus was heard to be on physical health checks for patients with a mental health problem (see NHS England, 2024b) and dealing with internal “reorganisation” due to national changes in the NHS. The investigation also observed that there was limited contact and collaboration between some mental health and physical health policy teams in national organisations, including for mental health and diabetes.

3.2.9 The investigation was also told by national organisations that ICBs had responsibilities for integrated services in their geographical areas. The investigation met with ICB representatives who described challenges influencing integration between mental health and specialist diabetes services. These included under-recognition of local need for integration due to data limitations; limited funding to develop and pilot services, and then sustain them (see 3.2.6); unclear evidence for which model of care would meet their population’s needs; and a lack of national direction and prioritisation of the need to integrate services (see 3.2.8). None of the ICBs referenced the work undertaken by Diabetes UK and NHS England (Sarchar et al, 2022).

3.2.10 ICB representatives also told the investigation about the wider challenges they were facing that prevented their ability to forward plan. At the time of the investigation, ICBs were undergoing review and restructuring which was impacting on their activities. Staff described concerns about not knowing what the future held which affected who was in role and therefore continuity in improvement programmes.

3.2.11 The gaps in integration between mental health and specialist diabetes services were found to be influenced by several factors, including limited national strategy to address the issue despite long-term recognition. Mental health teams shared concerns of an ongoing lack of championing to address the issue as it is of limited consideration in the Department of Health and Social Care’s (2025) ‘10 year health plan for England: fit for the future’. However, ICBs and national organisations also shared that the following may offer opportunities to support integration of services:

- **Modern service frameworks** – mental health is one of the first frameworks being developed to reduce mortality and support people to live better lives. This framework would benefit from ensuring patients with a mental health problem have access to specialist physical health services when required.
- **Neighbourhood health models** – being developed with a focus on accessible community-based services. Plans refer to MDTs for holistic joint care including between mental and physical health services (NHS England, 2025c). The investigation heard that there is an aspiration for integration between mental and physical health services but limited information, policy or guidance about how this should happen in practice.

3.2.12 In summary, the investigation found a lack of national strategy and local/regional planning to ensure patients with a mental health problem and diabetes have access to and support from specialist services. A lack of national commitment and leadership to address the issue was heard and that this influenced the commitment of provider organisations and ICBs. The investigation makes the following safety recommendation, and the above findings have contributed to the local-level and ICB learning in 5.2/5.3.

HSSIB makes the following safety recommendation

Safety recommendation R/2026/073:

HSSIB recommends that NHS England/Department of Health and Social Care develops a strategy for improving collaboration between mental health teams and specialist diabetes services, that includes consideration of responsibilities for integrated working at national, regional and local levels. This is to support future integration of services that will benefit all patients with mental health and diabetes care needs, including patients who are required to self-administer insulin and patients with type 1 diabetes and disordered eating.

Regulatory oversight of integration

3.2.13 The investigation met with the Care Quality Commission (CQC) to understand its role in inspecting the integration of mental health and specialist diabetes services. The CQC told the investigation that its inspections are confined to the scope of an organisation's registered activities and it does not extend beyond these boundaries. The teams inspecting mental and physical health services are separate and were heard to be unable to "step across". The CQC acknowledged that under their current model it is unable to undertake a holistic inspection around the needs of the patient group in this investigation.

3.2.14 HSSIB has previously recommended that the CQC scrutinises pathways between providers through its responsibilities to assess integrated care systems (ICSs). The CQC had been developing a new framework for assessments and previously confirmed that it would enable focus on cross-provider pathways (Health Services Safety Investigations Body, 2025b). Following a national review, the Government agreed to pause implementation and at the time of this investigation it remains on hold.

3.2.15 Similar to previous investigations by HSSIB (2025a; 2025b; 2025c) and its predecessor the Healthcare Safety Investigation Branch (2021), this investigation found gaps in the regulatory oversight of care pathways that would help drive improvements in patient safety. The CQC, to date, has not been enabled to do this despite recommendations highlighting the need. The CQC told the investigation that future plans for the regulatory oversight of neighbourhood health models (see 3.2.11) may provide opportunities to assess whether the holistic needs of patients are being met.

Admissions with diabetic ketoacidosis

3.2.16 The investigation heard concerns from several sources that where patients had repeated admissions to hospital with DKA, it may not be recognised that their mental health problem and associated self-restriction of insulin was contributing to the recurrence. Once the acute medical issue of the DKA has been treated, physical healthcare teams may not investigate the cause of the insulin restriction. Evidence suggests mental health problems are more frequent in people with recurrent DKA but that this may not be recognised (Garrett and Ismail, 2020; Garrett et al, 2021).

3.2.17 The identification and referral of patients to mental health services by acute hospitals was outside of the scope of this investigation. However, the investigation felt it important to recognise that there may be patients with diabetes (requiring treatment with insulin) who have not been identified as having a mental health problem. This finding has contributed to the local-level learning in 5.3.

3.3 Services for people with diabetes and specific needs

3.3.1 During its examination of the patient safety issue, the investigation recurrently heard about specific groups of people who were disadvantaged by the lack of integration between mental health and diabetes services. These included people diagnosed with a personality disorder (see 4.1), people with T1DE and people experiencing homelessness.

Type 1 diabetes and disordered eating (T1DE)

3.3.2 Megan (see 2.2) was considered to have T1DE (see 1.3.6) and her family shared the challenges she faced accessing care for both her mental health and her diabetes. Megan did not have access to specific services for the support of patients with T1DE and the investigation identified other patients with T1DE who had had limited support and who had died.

3.3.3 Recognition of T1DE has grown in recent years with suggestion that it may be a specific condition, and proposed criteria for identification have been published (Royal College of Psychiatrists, 2022a; Ismail et al, 2024b). It is estimated that about 5% of people with an eating disorder and type 1 diabetes have severe T1DE, and patients with T1DE have a higher overall likelihood of death compared to the general population (Breakthrough T1D, 2024).The investigation considered T1DE from the perspective of adult patients but also heard that the condition can affect all ages. The importance of early detection in children and young people was highlighted (O’Donnell et al, 2022).

3.3.4 The investigation was told that T1DE is not widely acknowledged in practice or screened for. T1DE is not specifically referenced in national guidance (for example, National Institute for Health and Care Excellence, 2017; 2022a; 2023a) or in healthcare training curricula (for example, JRCPTB, 2022; Royal College of Psychiatrists, 2022b). This means that patients are not being recognised and limited recognition means the prevalence of T1DE is unclear which affects service planning and commissioning. Patients may present in different ways including through repeat admissions to hospital with DKA (see 3.2.16); they may also go undetected when they have not required an emergency admission to hospital.

3.3.5 To support someone experiencing T1DE, a patient’s multiple and individualised needs require consideration (Embick and Stewart, 2025). A multidisciplinary team model of care has shown benefits including improved management of blood sugar levels and reduced admissions to hospital with DKA (Zaremba et al, 2022; Stadler et al, 2025). Services require design in collaboration with people with lived experience and involve specialists in mental health (eating disorders), type 1 diabetes and other professions such as dietitians (Royal College of Psychiatrists, 2022a).

3.3.6 In 2019, two pilot services were set up for patients with T1DE and demonstrated several positive outcomes for patients. Subsequently, five further sites were funded by NHS England until the end of March 2026 to cover a wider proportion of the country. Following March 2026, the investigation was told that the intent was for ICBs to continue funding of T1DE services. However, staff and families shared concerns about the long-term funding of T1DE services in England. At the time of the investigation, some ICBs had extended funding for their regional T1DE services beyond March 2026 but other services had ceased taking referrals.

3.3.7 Representatives from some of the pilot sites told the investigation that T1DE services required significant resource but that this was needed because of the complexity of patients' needs (Ismail et al, 2024b). They also described that the resource had wider benefits including reductions in patients attending hospital in DKA and reducing the potential for long-term diabetes complications that would require input from healthcare services. Where local funding had been achieved for one of the services, this was heard to be because the business case had made clear that it was "an intervention" to fundamentally change how people interact with services.

3.3.8 The investigation engaged with national stakeholders, charities and researchers to explore the wider context around the care of patients with T1DE. Challenges were described that affected the recognition of T1DE and the long-term funding of services. These included "disagreement" on diagnostic criteria, limited clarity about the best model for care, the high cost of services for a small group of patients, and the potential to create inequitable access to care for other patients who may benefit from similar services. These challenges were heard to exist alongside the limited integration between mental health and diabetes services and limited availability of services for people with an eating disorder (All-Party Parliamentary Group on Eating Disorders, 2025).

3.3.9 Regarding T1DE as a formal diagnosis, the condition may be known by different terms (see Shelford et al, 2025) and the investigation heard varying views about what T1DE is, whether it is a specific/discrete condition or not, and whether it is already recognised as part of another condition. T1DE or 'diabulimia' are not explicitly included in diagnostic classification systems – the World Health Organization's (2019) International Classification of Diseases (ICD, 11th edition) and the American Psychiatric Association's (2022) Diagnostic and Statistical Manual of

Mental Disorders (DSM, 5th edition). The investigation was also told that T1DE is represented in DSM (5th edition) as an ‘Other Specified Feeding or Eating Disorder’ as this includes ‘Purging disorder’ which describes behaviour to influence weight including misuse of ‘medications’.

3.3.10 Regarding the model of care for people with T1DE, the investigation was told that the “best” model is unclear. There were also concerns that any model for a highly-specialist service may deskill staff in eating disorder or diabetes services. The lack of clarity around the model was heard to be because the underlying condition and the factors contributing to it have not been agreed, and because of limited research exploring different models. The investigation observed differences in how some T1DE services had been designed but also heard that they share the same principle of “good mental health care and diabetes support”.

3.3.11 At the time of writing, publication of a rapid evaluation of impact of the T1DE pilot sites was imminently due (National Institute for Health and Care Research, 2023b). The investigation was told by national stakeholders that this evaluation would inform decisions about the commissioning of services. Concerns were also heard about the ability of the evaluation to draw conclusions when there is limited agreement about what T1DE is and because sites had only cared for a small cohort of patients over a relatively short period of time. The need for further research into T1DE has already been highlighted (Breakthrough T1D, 2024) and the investigation heard about gaps that need to be filled. The gaps included knowledge around underlying mechanisms of disordered eating in type 1 diabetes, the prevalence of T1DE, management approaches, and health economics of services.

3.3.12 The investigation heard – from patients, families and staff working in T1DE services – clear support for T1DE to be recognised as a condition and for appropriate services to be commissioned. Should T1DE services be challenged in the future by a lack of funding, a strategic plan to care for these patients is needed and so this finding has contributed to the safety recommendation in 3.2.12.

3.3.13 The investigation also heard that funding decisions around T1DE services were complicated because of the financial challenges facing the NHS and because of the questions yet unanswered about T1DE. The investigation found a need for further research into the combination of type 1 diabetes and disordered eating to help inform future decision making in support of services and therefore patient safety.

HSSIB makes the following safety recommendation

Safety recommendation R/2026/074:

HSSIB recommends that the National Institute for Health and Care Research, in collaboration with relevant research and policy stakeholders:

1) maps the knowledge gaps surrounding type 1 diabetes and disordered eating (including those identified in this investigation); and

2) assesses the priority and feasibility of commissioning research to help address those gaps.

This is to help develop new knowledge to inform future decisions for the delivery of safe and effective care for this group of patients.

3.3.14 The investigation recognises that any research will take time and require funding. In the meantime there is evidence of ongoing harm to patients with type 1 diabetes and forms of disordered eating. National stakeholders described a need for “action now” with recognition that research findings will shape future actions. In the short term, “disagreements” were heard to be limiting the identification and “coding” of patients with T1DE that affected understanding of prevalence. The investigation found a need for greater recognition and awareness of the co-existence of type 1 diabetes and disordered eating, along with improved information and support for both patients and healthcare professionals.

HSSIB makes the following safety recommendation

Safety recommendation R/2026/075:

HSSIB recommends that Royal College of Psychiatrists, through collaboration with relevant stakeholders, develops a strategy that:

1) supports consistent recognition of patients with type 1 diabetes and evidence of disordered eating; and

2) identifies associated care responsibilities for providers of mental and physical health services.

This is to help improve the NHS’s recognition of patients who are affected and to support decisions around the commissioning of services.

3.3.15 The investigation also met with NICE to explore the contents of relevant guidelines, including those for diabetes and eating disorder. NICE (2017; 2022a; 2023a) guidance recognises the co-existence of diabetes and eating disorders/ disordered eating, and guidance refers to the risks of misuse of insulin. The guidance does not specifically name T1DE. NICE told the investigation that their guidance looks to align with diagnostic classifications and noted the variation around terming/classification of T1DE. NICE shared that guidance would likely be reviewed in light of new research or findings supporting clarification of T1DE as a condition and if specific evidence-based interventions are identified.

Services for people experiencing homelessness

3.3.16 During engagement with mental health teams, the investigation heard about the unmet needs of people experiencing homelessness. Around 80% of people experiencing homelessness have a mental health diagnosis (Homeless Link, 2022) and the rates of diabetes in this population are higher than the general population (The Queen's Nursing Institute, 2024). Patients face ‘numerous barriers’ to effective self-management of diabetes.

3.3.17 Supporting people experiencing homelessness who have diabetes (requiring treatment with insulin) and a mental health problem was described as “particularly challenging” (Pathway, 2024a). Patients also told the investigation that their circumstances made them feel “hopeless” which made them less motivated to effectively manage their insulin. They also did not have the ability to attend appointments that required going at fixed times.

3.3.18 The investigation shadowed staff who ‘outreached’ to work with people experiencing homelessness, including to support insulin management and mental health. Services were not available across the country as “the picture varies everywhere”, determined by local funding decisions. Where services had been established, these were based on recognition of local need through analysis of data. Examples included:

- **A general practice inclusion team** – this included a service for people experiencing homelessness or living in a hostel in the area. The service included GPs, nurses, addiction specialists and social workers. The service had ‘drop-in’ clinics and input from a diabetes specialist nurse once a week.
- **A homeless nursing team** – a pathway was created after recognition by a diabetes specialist nurse of the need to support patients with ‘crisis management’ when they are without their insulin. The pathway has helped mitigate difficulties faced by patients experiencing homelessness who may

present out-of-hours and may not have a GP. The service is multidisciplinary and focuses on providing holistic and equitable diabetes care.

- **Street homeless support** – a specialist team responding to the needs of people sleeping on the street with mental and physical health difficulties. The service covered a specific area, linked with charitable support and the local authority. It had a ‘hub’ in a hall where people could drop in and see a variety of practitioners, including mental health and diabetes specialists.

3.3.19 The investigation heard that where services did not exist, in some areas it was because the need was not there. However, with increasing numbers of people experiencing homelessness (Office for National Statistics, 2025) and concerns heard about the quality of local data, it was difficult to conclude whether needs had been effectively understood. “Prejudiced beliefs” about people experiencing homelessness were also described that may influence investment decisions; stigma, racial bias and systemic discrimination are reported to affect people experiencing homelessness (Guise et al, 2025).

3.3.20 The investigation met with Pathway – a UK homeless and inclusion health charity – which has published findings considering the experiences of people experiencing homelessness and diabetes (Pathway, 2024b). Pathway described the need for a collaborative health and social care response to support people in this situation, but said there was a lack of national discussion to prioritise such support. HSSIB (2025a) has previously highlighted the need for collaboration between health and social care services for people with a mental health problem.

3.3.21 The investigation found that people experiencing homelessness face challenges accessing support for their mental health and diabetes care. While some services exist that reach out into homeless communities, they are not accessible to all. Pathway (2024a; 2025) has produced resources to help services support people experiencing homelessness, but limited services mean people face inequitable access to care. This finding has contributed to the ICB learning in 5.2.

3.4 Barriers to information sharing

3.4.1 The investigation identified other factors that influenced collaboration between mental health and diabetes services. A repeated issue was that IT systems did not facilitate transfer of information about a person’s contact with different services, including across the NHS and independent sector. This is a known issue highlighted by HSSIB (2025d) investigations.

3.4.2 Community mental health teams were observed to be unable to access information about their patients where it was held in a different IT system to the one in their organisation. The result was that staff “don’t know what is going on” and were unaware if patients had been seen by another service.

3.4.3 The investigation found that interoperability of IT systems across mental and physical health services was a factor that contributed to patient safety incidents. This finding has contributed to the local-level and ICB learning in 5.2/5.3.

4. Analysis and findings – care for patients experiencing a mental health crisis

This section focuses on therapeutic care – the forming of partnerships between staff and patients with recovery-focused goals – for patients experiencing a mental health crisis, and access to insulin when a patient is at risk of self-harm.

Because of the nature of the patient safety issue, the investigation examined why a person may self-harm and how services can support patients to reduce their potential for self-harm. The investigation heard about challenges supporting patients who need access insulin and who are experiencing a mental health crisis (see 1.3.2). Alex and Megan experienced mental health crises that contributed to self-harm.

4.1 Therapeutic care for patients experiencing a mental health crisis

4.1.1 Several of the community mental health teams engaged with had known patients who had died by suicide or following self-harm with insulin. Teams told the investigation that, where they had been unable to form therapeutic relationships, they had been unable to support the patient to understand their thoughts and feelings, or to develop plans should they have thoughts to self-harm. Factors preventing the forming of therapeutic relationships included demand on services, acuity of patients with complex and multiple needs, workforce shortages, and limited availability of specialist services including for social issues.

4.1.2 A repeated issue heard was the lack of specialist services for people with a diagnosis of personality disorder; this has been highlighted by another HSSIB (2024a) investigation. Several of the patients involved in the incidents considered by the investigation, including Alex, had a diagnosis of personality disorder. Evidence suggests and the investigation heard that a large proportion of people who self-harm with insulin may have an underlying personality disorder (Garrett et al, 2021). The intense and changeable emotions that may be the sign of a personality disorder can mean a person will rapidly develop an overwhelming urge to self-harm.

4.1.3 Patients with a diagnosis of personality disorder were described as being at “very high risk” and needing of long-term therapeutic care with multidisciplinary specialist input (National Institute for Health and Care Excellence, 2009). Due to the factors in 4.1.1, community mental health teams were often not able to meet those needs. Some dedicated services were seen in some NHS trusts, but they varied depending on where a person lived, with differences in waiting lists and criteria for acceptance. This variation has been described by the Royal College of Psychiatrists (2020b).

4.1.4 It was beyond the scope of this investigation to examine the availability of services for people with a diagnosis of personality disorder. However, it was heard that “personality disorder is poorly managed in the UK” and the investigation found evidence to suggest gaps in the availability of services able to provide the psychosocial interventions needed by patients.

Assessment of risk where a patient has access to insulin

4.1.5 In both Alex’s and Megan’s care, concerns were shared with the investigation that the assessments of their risk of self-harm had not effectively recognised their potential for further episodes or the ease of access to insulin. In Alex’s case, her family also described under recognition of how the rapid and extreme fluctuations in her emotions led to her self-harm. HSSIB (2024b) has previously highlighted safety concerns about continued use of risk assessment tools that provide a risk score for self-harm; this is despite NICE (2022c) guidance recommending a move to assessments that provide a more effective understanding of risk factors.

4.1.6 Mental health teams talked the investigation through their risk assessments of patients. While most of these aligned with NICE (2022c) guidance – such as considering protective factors to help manage a person’s self-harm thoughts – some teams still described knowing patients who were “low risk” who had gone on to die by suicide. As NHS England (2025d) has described, the ‘’low-risk paradox’ – that most people in contact with mental health services who die by suicide have been assessed as being at low or no risk of suicide – shows that suicide prediction tools, scales and stratification do not work. In response, NHS England (2025d) has published best practice guidance for safety assessment and management.

4.1.7 Specific to insulin, several teams described a patient’s access to insulin as a “red flag”. Others described only a superficial knowledge of the dangers of insulin and staff were not always familiar with the different types and varying speeds of onset. It was heard that limited knowledge meant under-recognition of the dangers of insulin. Some staff also described a danger that repeated episodes of self-harm with insulin may be “normalised” and not be seen as “significant”.

4.1.8 Regarding mental health teams’ knowledge around insulin, a previous HSSIB (2024a) investigation included exploration of the content of pre-registration mental health nursing education; this highlighted that the Nursing and Midwifery Council’s (NMC) (2018) updated standard for education included greater coverage of physical healthcare and reference to conditions including diabetes. Despite this focus, the investigation heard that diabetes care and insulin was under-considered in mental health nursing education. The NMC has previously told HSSIB that it is the responsibility of institutions to develop and implement curricula to meet the standards.

HSSIB makes the following safety observation

Safety observation O/2026/081:

Organisations involved in the provision of undergraduate and pre-registration education and preceptorship/induction programmes can improve patient safety by ensuring that staff have knowledge of diabetes, an understanding of how and why insulin is a vital treatment for many people with diabetes, and the risks that the use and misuse of insulin can present for patients with a mental health problem.

4.1.9 The investigation also identified other factors that influenced how staff consider a patient’s risk of self-harm. These included limited involvement of families in assessments (see 4.1.15) and staff making assumptions about patients based on there behaviours, circumstances and characteristics. Both Alex’s and Megan’s families described that they had been taken “less seriously” and considered “less vulnerable” due to them being bright, articulate and from more privileged backgrounds.

4.1.10 Further examination of the assessment of risk of self-harm was beyond the scope of this investigation. However, HSSIB (n.d.) has launched separate work considering safety issues for people experiencing a mental health crisis and this investigation will contribute to that work. This investigation's findings have also contributed to the local-level learning in 5.3.

Assessment of mental capacity

4.1.11 A repeated concern shared by families whose loved ones had self-harmed was how assessment of mental capacity had concluded that they (the patient) had capacity to make specific decisions and "unwise decisions" about their self-care and insulin. In several incidents, the investigation saw conclusions stating that the patient 'had capacity', the risk of self-harm was 'chronic', and following self-harm there was 'no new learning'. The investigation explored assessment of mental capacity under the Mental Capacity Act (MCA) (2005) with those it engaged with.

4.1.12 Families and some staff questioned whether assessment of a patient's mental capacity by a healthcare professional, in relation to self-harm and insulin, could be effectively undertaken if the professional is not themselves aware of the risks associated with insulin or the underlying condition involved. Staff also described how assessment under the MCA was "difficult" and the investigation heard from national stakeholders that the MCA was "poorly understood". Challenges applying the MCA in practice have also been identified in other HSSIB (2023) investigations.

4.1.13 Specifically, the investigation heard repeated concerns about the undertaking of the "functional test" within the assessment of mental capacity. This test includes exploration of a patient's ability to "weigh-up pros and cons" of a decision but was heard to be "complex" to undertake. Assumptions may be made that someone is able to weigh-up decisions without first exploring whether a mental or physical health problem is influencing their thoughts, including their blood sugar levels.

4.1.14 The MCA was also described as "not good" when a person's capacity may fluctuate rapidly. In relation to Alex's care, her family described that she lost capacity to decide to administer her insulin safely when her emotions reached extremes. At the point her capacity was assessed, she potentially had the ability to keep herself safe but there was no proactive safety planning for when she lost capacity. Due to the concerns identified around the MCA in practice, the investigation will consider this further in the next report in this series. In the meantime, this finding has contributed to the local-level learning in 5.3.

Family involvement in a person’s care

4.1.15 In both Alex’s and Megan’s care, there were points where they did not consent to the sharing of information about their care with their families; they were deemed to have capacity to make those decisions by mental health teams. This meant their families did not have a complete understanding of their risk of self-harm, and therefore could not act in a protective capacity, for example by supporting them with their insulin.

4.1.16 Several families told the investigation that they questioned whether their loved ones truly understood the life-threatening ramifications of refusing them access to information, and whether they had been able to weigh up the benefits and risks. Mental health staff told the investigation that, if a patient has capacity and refuses sharing of information, “then that is their decision”. There may be reasons why a patient does not want information shared. However, staff also acknowledged that refusal to share information may not be explored with the patient, or returned to should the patient reconsider their decision.

4.1.17 The investigation observed several occasions where discussions took place between staff and patients about speaking to relatives and sharing information. Patients often gave their consent, but for those who refused, the investigation did not see exploration of why. The investigation was unable to determine whether these were informed choices by the patient. This finding has contributed to the local-level learning in 5.3.

4.2 Access to insulin and the risk of self-harm

4.2.1 Therapeutic mental health care seeks to reduce the risk that a patient will self-harm by equipping them with an understanding of their thoughts and behaviours, and tools to de-escalate self-harm thoughts. However, as shown by the incidents in this investigation, de-escalation is not always effective. In these situations, restricting access to methods for self-harm may allow time for a person’s thoughts of harm to subside.

4.2.2 Community mental health teams told the investigation that they were in a “difficult” position when it came to restricting a patient’s access to insulin. They recognised the critical need for some patients to have timely access but also that access carried its own risk. This presented a complex and challenging situation, requiring a balanced approach to mitigate both physical health risks and self-harm concerns. The issues described in 3.1.6 relating to access to specialist diabetes advice contributed to the teams’ challenges.

4.2.3 The investigation examined available options for restricting a patient's access to insulin. This was heard to be easier for someone with type 2 diabetes because they may only require a long-acting insulin at a specific time of the day. Someone with type 1 diabetes may need variable doses of rapid-acting insulin throughout the day and a long-acting insulin. The investigation considered:

- alternatives to self-administration of insulin
- insulin pen devices
- other technologies.

Alternatives to self-administration of insulin

4.2.4 This investigation focused on patients with a diagnosis of diabetes requiring treatment with insulin. However, the investigation recognises that, in relation to type 2 diabetes, it may be possible to avoid the need for insulin through diabetes prevention or early effective control of blood sugar levels. This highlights the importance of public health programmes and early type 2 diabetes management to reduce future risk.

4.2.5 Where patients were prescribed insulin, alternatives to patient self-administration were heard to potentially reduce the risk of self-harm. Staff described restriction of access to insulin as a short-term solution, but that in the longer term this could lead to disempowerment which was not supportive of recovery. The investigation heard about various alternatives to self-administration, but these were not always feasible. They included:

- **Community nursing team (CNT) administration** – few examples were seen where a CNT administered insulin to a patient for the reasons explored in this investigation. CNTs were often not commissioned for care where a person was able to self-administer and was not housebound. CNTs could not guarantee visiting at required times or being able to visit if extra insulin was required, and this risked the patient not having access to rapid-acting insulin when they needed it.
- **General practice or pharmacy administration** – no examples were seen but examples were suggested to exist. Similar challenges to those with CNT administration were described. General practices and community pharmacies were not always open at weekends which was a further barrier.
- **Family administration** – several families described supporting their loved ones with administration and keeping insulin hidden. This option depended on

the availability and willingness of the family, the relationship between family and patient, and information available to families (see 4.1.15).

4.2.6 Some staff also questioned whether there were alternatives to insulin that could be considered. For patients with type 2 diabetes who had been prescribed insulin, projects were seen to deprescribe (stop) insulin where appropriate. Deprescribing was not an option for patients with type 1 diabetes; for some patients, their insulin regimens had been simplified but this did not always provide ideal management of their blood sugar levels.

4.2.7 Despite some attempts to restrict patient access to insulin, the investigation also saw examples where patients had still been able to access it. In these cases access was through routes not intended for them to use (further details intentionally not provided) and where insulin had been dispensed by pharmacies because the decision to reduce the amount prescribed to a patient had not been communicated.

Insulin pen devices

4.2.8 The investigation explored insulin pen devices available in the UK that may help reduce the risks of intentional excess dosing; no device was identified that would reliably eliminate the risk. ‘Smartpens’ linked to apps were seen that provided information for tracking administration timing and dose but these did not have functionality that would address the safety issue. Diabetes specialists told the investigation that smartpens may make it easier for a patient or carer to monitor doses administered, but would not prevent excess administration.

4.2.9 The investigation approached manufacturers of insulin pens to explore design. Manufacturers confirmed that they did not produce a pen with functionality that would prevent intentional excess administration of insulin. Some pens had functionality to help reduce the risk of unintentional overdose and others included ‘smart’ technology to record doses administered, but that would not prevent excess administration.

4.2.10 The investigation met with national organisations representing industry and innovation to explore options for future pen design. Seeking a new pen design or change was described as a “challenge” because, in relation to the patient safety issue, pens were being used outside of how they were intended to be used and this was not considered a design problem. It was heard that the technology is working as intended and, without evidence of significant risk, manufacturers may not prioritise a change to design.

4.2.11 Regarding evidence of the risks associated with pen devices, “quantitative evidence” of the risk was heard to be needed that proved “actual” harm. Manufacturers told the investigation that they relied on users to submit issues to them and data from the Medicines and Healthcare products Regulatory Agency (MHRA). User reports had not demonstrated to manufacturers the patient safety issue, but it was heard from patients and families that the issue was unlikely to be reported.

4.2.12 The MHRA shared the data it had received about overdoses of insulin with the investigation. The MHRA told the investigation that it did not feel it had a good understanding of the risk due to limitations in the data reported to their Yellow Card system. From a healthcare provider perspective, this relied on manual reporting as there is no automated connection between the NHS’s Learning from Patient Safety Event and MHRA’s Yellow Card system.

4.2.13 Limitations in incident data have been identified by several HSSIB investigations to influence recognition of certain patient safety risks. However, while the incident data may not always be available, the findings of this investigation and the narratives from patients, families and staff clearly demonstrate the risk associated with insulin pen devices and self-harm.

4.2.14 In relation to the monitoring of safety issues with medical devices, in June 2025, The Medical Devices (Post-market Surveillance Requirements) (Amendment) (Great Britain) Regulations 2024 were passed into law. The investigation was told that these updated regulations had the potential to improve data in relation to the patient safety issue because of expectations set on the MHRA and manufacturers ‘to proactively collect and review experience gained from devices… for the purposes of identifying any need to apply corrective or preventive actions’.

4.2.15 The investigation found that there are no insulin pen devices designed in a way that would prevent a patient from intentionally administering excess insulin. Limitations in the spontaneous data collected by manufacturers and the MHRA means the patient safety issue is under-recognised. The MHRA told the investigation that it is not their role to ask manufacturers to change products or design new ones without a confirmed safety concern because they are an independent regulator. HSSIB also has no legislated ability to make safety recommendations directly to manufacturers. As such, only a safety observation can be made.

HSSIB makes the following safety observation

Safety observation O/2026/082:

Organisations involved in the manufacture of insulin pen devices used by the NHS can improve patient safety by:

1) understanding where devices are being used outside of their intended purpose; and

2) exploring the potential to design devices that would reduce the risk of intentional overdose of insulin for self-harm.

Other technologies – continuous glucose monitors

4.2.16 The investigation also explored access to other technologies that may support the safe self-administration of insulin. These included continuous glucose monitors (CGMs) and insulin pumps, including hybrid closed loop (HCL) systems (see 1.1.8). Other innovations are also increasingly being launched, including automated, wearable and tubeless technology.

4.2.17 Specialist diabetes staff described the benefits of CGMs, specifically that they blood sugar levels can be monitored ‘in the moment’ and over time without a patient needing to take a blood test. This can reduce the “burden” of diabetes which may be beneficial when someone is finding self-care difficult. NICE (2022a; 2022b; 2023a) recommends that all patients with type 1 diabetes and some patients with type 2 diabetes have access to CGM.

4.2.18 The investigation met multiple patients with type 1 diabetes who were under the care of community mental health services. A small number of these patients had a CGM. Some patients told the investigation that they had never been offered a CGM, while others had not been able to use one. Mental health staff again described that there may be assumptions made that a patient cannot use technology because of their mental health problem.

4.2.19 Where patients had a CGM, mental health staff recognised the potential benefits for the patient to help manage their physical health and reduce the mental burden of their diabetes. They considered that ‘remote monitoring’ – by a healthcare professional or family member away from the patient – may be useful if monitors were able to alert the professional to out-of-range sugar levels in real time. The investigation explored a case where remote monitoring of a CGM by a patient’s family had allowed the family to recognise a dangerously low sugar level and call for help.

4.2.20 While the investigation heard about potential benefits of remote monitoring of blood sugar levels, it did not see examples where this was in place. Barriers to using a CGM included patient, staff and infrastructure factors. From a patient perspective, “paranoia” about being monitored may affect their willingness to engage with a CGM. Mental health staff also described how they would not feel comfortable interpreting the results of a CGM and would require specialist input. From an infrastructure perspective, healthcare IT was not in place to make remote monitoring a reality, with questions over who would fund connections and where results would be monitored.

Other technologies – hybrid closed loop systems

4.2.21 The investigation did not see any patients with a mental health problem who had an insulin pump or HCL system. Perceptions were heard that HCL systems may be “safer” for patients. On exploring this with specialists, it was heard that HCL systems may reduce the potential for administering excess insulin but would not remove the risk; systems contain rapid-acting insulin and a patient would still need an insulin pen as a “back-up”. HCL systems do, however, reduce the mental burden associated with diabetes and insulin (National Institute for Health and Care Excellence, 2023b).

4.2.22 The investigation explored the barriers to a patient with a mental health problem being prescribed an HCL system if they meet NICE (2022a; 2023b) criteria. As in Alex’s case, the investigation heard examples where patients had not been offered an HCL system. Mental health staff described that, similar to CGMs, assumptions may be made that a patient is unable to use an HCL system due to their mental health problem. In contrast, the investigation learned about a specialist diabetes service that had clear safety criteria for placing a patient with a mental health problem on an HCL system; that service had seen positive outcomes for several patients including where HCL systems had reduced the burden of injection and decision making.

4.2.23 Inequalities associated with access to diabetes-related technology have been recognised with calls to assess and support patients to access technology rather than deny it (for example ABCD Diabetes Care, 2023). The investigation found evidence that technology may be being denied to some patients with a mental health problem, and the Equality and Human Rights Commission (2020) have highlighted that this may, in certain circumstances, represent discrimination. This finding has contributed to the local learning in 5.3.

5. Analysis and findings – regional and local learning

5.1 Summary

5.1.1 This investigation found that the healthcare system is unable to consistently meet the needs of patients with a mental health problem and diabetes (requiring treatment with insulin). Limited integration between mental health and specialist diabetes services, and barriers to providing specific elements of mental health care, contribute to the situation.

5.2 Learning for integrated care boards

5.2.1 HSSIB investigations include safety learning for integrated care boards (ICBs) where this may help them to think about how to respond to a patient safety issue across their geographical footprint. The investigation proposes the following safety learning for ICBs.

Safety learning for integrated care boards ICB/2026/014:

HSSIB suggests that integrated care boards formalise collaborations between mental health and specialist diabetes services in their local systems. Through co-production with people with lived experience, this should look to include:

- care arrangements for people with a mental health problem and diabetes, particularly for those who require insulin
- routes for community mental health teams to access advice where their patients have diabetes and access to insulin
- routes for diabetes specialist teams to seek advice from mental health teams about reasonable adjustments for patients under the care of outpatient clinics
- enablement of interoperability between electronic systems to support information sharing.

Safety learning for integrated care boards ICB/2026/015:

HSSIB suggests that integrated care boards develop data-driven approaches for the understanding of local need to inform decisions about services for patients who have been identified as marginalised in this investigation. These are patients with:

1) co-existing mental health and long-term physical health needs (diabetes), including those with a diagnosed personality disorder and/or experiencing homelessness; and

2) type 1 diabetes and disordered eating.

5.3 Local-level learning

5.3.1 HSSIB investigations also include local-level learning where this may help providers/organisations respond to a patient safety issue at the local level. The investigation shares the following local-level learning.

For organisations providing mental health and/or specialist diabetes services:

- Does your organisation have a specific job role with responsibility for cross-organisational care pathways to ensure the holistic needs of patients, including those with mental health problems and diabetes, are met?
- How does your organisation ensure information about patients is available to other providers of care when required, for example to mental health teams about a patient’s diabetes care?
- How does your organisation ensure staff are aware of their responsibilities to report incidents associated with diabetes medication and technology, including to manufacturers and the Medicines and Healthcare products Regulatory Agency?
- Does your organisation have a process for identifying and appropriately supporting patients with type 1 diabetes who also have evidence of disordered eating?

For organisations providing specialist diabetes services:

- How does your organisation ensure patients with a mental health problem are not being discharged from clinics following a ‘did not attend’ without consideration of their circumstances and risks to their safety?
- Do your staff recognise the need to make reasonable adjustments for patients, including for those with a mental health problem, to support access to care?
- Does your organisation have a liaison psychiatry service that supports inpatient and outpatient services for people with a mental health problem?
- Does your organisation have clear routes via which services can seek support from specialists in mental health if a patient is found to be experiencing a crisis?
- How does your organisation identify patients who have had recurrent admissions with diabetic ketoacidosis or hypoglycaemia, and support staff to consider whether these patient require input from mental health services?
- How does your organisation ensure patients with a mental health problem, who meet the criteria for diabetes technology, are receiving support to access it and are not being discriminated against because of their mental health problem?

For organisations providing mental health services:

- How does your organisation ensure staff working in the community have access to advice about a patient’s physical health, including specialist advice for conditions such as diabetes requiring treatment with insulin?
- How does your organisation keep staff up-to-date about the different types of insulin used in the NHS and their onset times to ensure this is considered as part of assessment of a patient’s risk of self-harm?
- How does your organisation enable staff to work therapeutically with patients to support them to develop safety plans which include consideration of the risks associated with insulin?
- How does your organisation support multidisciplinary discussion in discharge planning that recognises the circumstances a patient is being discharged into to ensure they are appropriate for their mental and physical health needs?

- How does your organisation support staff to make assessments under the Mental Capacity Act, with particular consideration of whether the patient can use and weigh information as part of their decision making?
- Does your organisation provide services that effectively meet the needs of people with rapidly fluctuating and extreme emotions, and that consider how best to support these patients when they are unable to make decisions to keep themselves safe?
- Do your staff recognise the importance of family involvement in patient care, and where the patient refuses this, do staff ensure the reasons for refusal and the potential ramifications are explored and it is appropriately revisited over time?
- How does your organisation support staff to not make assumptions about patients based on their circumstances and characteristics?

6. Glossary

The terminology in this report has been chosen while acknowledging that there are differing views across organisations and groups.

Assertive outreach	Intensive community-based engagement, treatment and follow-up, particularly for patients who may have disengaged from services (see NHS England, 2025b).
Continuous glucose monitor (CGM)	A wearable device that provides intermittent or real-time readings of a person’s interstitial fluid sugar level.
Diabetes (mellitus)	A condition where the level of sugar in a person’s blood is too high. In type 1 diabetes the person’s pancreas does not produce insulin. In type 2 diabetes the person’s body does not produce enough insulin or the body's cells become resistant to insulin (Diabetes UK, n.d.a).
Diabetic ketoacidosis	A life-threatening diabetes complication caused by a severe lack of insulin. Without enough insulin, the body cannot use sugar for energy and so it starts to break down fat and muscle, leading to harmful accumulation of acids in the blood (ketones).
Functionality	Relates to whether the capabilities and features of a device meet the needs of users when looking to achieve their goal.
HbA1c	

	Glycated haemoglobin – the amount of sugar sticking to red blood cells. Testing HbA1c provides an indication of a person’s average blood sugar levels in the previous 2 to 3 months.
Hyper/ hypoglycaemia	Too high or too low blood sugar levels.
Hybrid closed loop system	A wearable system that involves an insulin pump and continuous glucose monitor ‘talking to each other’ to automatically adjust the insulin dose being administered outsider of meal times.
Insulin	Medication used in diabetes to regulate blood sugar levels. A rapid-acting insulin may onset (take effect) in 5 to 15 minutes, while a basal (background/long-acting) insulin may onset in 2 hours and last 18 to 42 hours.
Integrated care boards (ICBs)	Statutory bodies that carry out several functions including facilitation of integration between NHS organisations.
Interoperability	The ability of a [IT] system or a product to work with other systems or products without special effort.
Information technology (IT) systems	The computer systems, hardware, software and networks in an organisation.
Mental health problems	Also referred to as mental illness. Disturbance of a person’s mental wellbeing, impairing their ability to function as they would do normally (Mind, 2017).
Personality disorder	A mental health condition that means a person may think, feel, behave or relate to others differently from other people (NHS England, 2024c).
Reasonable adjustment	Changes that disabled people may need to access the same services/opportunities as people without a disability.
Secondary mental health services	Specialist mental health services that include community mental health teams, crisis teams, home treatment teams and hospital teams.
Self-harm	Any behaviour where someone causes harm to themselves; this may be to help cope with difficult thoughts and feelings (Mental Health Foundation, n.d.).
Self-administration	Where a person administers their own medication.
Therapeutic engagement and relationships	Partnership between staff and patient with shared decision making and recovery-focused goals (Care Quality Commission, 2023). Relationships embody core values such as respect, compassion, trust and kindness.

Type 1 diabetes and disordered eating (T1DE)	A condition where a person has an eating disorder or disordered eating behaviours and type 1 diabetes.
Trauma-informed approach	Care grounded in the understanding that a patient's past exposures to trauma will influence their development and how they respond to situations.

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8. Appendix

Investigation Approach

Terms of reference

Through engagement with patients, families, staff and organisations/providers of primary, community and secondary mental health and diabetes care, the investigation examined the following in relation to people with a mental health problem and diabetes:

- What are the core processes involved in care for patients who self-administer insulin in community settings?
- How do patients access support for their insulin in relation to administration, monitoring and in the long-term?
- What other intersectional factors influence the care of patients?

The investigation began with a focus on the care received by patients and delivered by organisations. It then progressed to engage with regional and national bodies.

Evidence gathering

The investigation engaged with and/or visited the organisations/providers shown in table A. Further evidence was gathered from policy and academic literature, the Strategic Executive Information System (StEIS) and the Learning from Patient Safety Events (LFPSE) system (national databases that capture information about patient safety incidents), and reviews of reports to prevent future deaths (PFDs).

Table A Evidence gathering and engagement

Evidence source	**Details**
StEIS – serious incident search	Events submitted 1/01/2023 – 30/09/2025, n = 23,413. Filtered by description ('insulin', n= 1924), n = 255. Further narrowed and reviewed by service area.
LFPSE – patient safety incidents	Events submitted 1/10/2023 – 30/04/2025, n = 54,065. Filtered by drug involved ('insulin', n = 1725) OR description ('insulin', n= 1924), n = 2334. Further narrowed and reviewed by service area and date.
Reports to prevent future deaths (PFD) – search	Report dates 01/01/2023 – 01/12/2025. Filtered by keyword 'insulin', n = 14.

Evidence source	Details
Patient and family insights	Patient and family insights through interviews and observations during the course of the investigation. Engagement throughout the investigation with the families of Alex and Megan.
Primary care	General practitioners, pharmacists and nursing staff from services across England. Including staff involved in inclusion health and diabetes.
Mental health care	Multidisciplinary mental health teams from services across England. Representation from community, crisis, liaison, physical health, homeless support, and patient safety teams. Including nursing, medical, pharmacy, social work and allied health professions. Site visits to three mental health organisations.
Specialist diabetes services	Consultant diabetologists and diabetes specialist nurses from services across England.
Integrated care boards	Leads of long-term conditions, nursing and quality representing systems across England.

Analysis of findings

Findings were identified following triangulation of evidence and consultation. Various analysis approaches were used including AcciMaps (Rasmussen, 1997) and the Systems Engineering Initiative for Patient Safety (SEIPS) (Holden et al, 2013).

Stakeholder engagement and consultation

The investigation engaged with the stakeholders listed below who contributed evidence to the investigation. Stakeholders also contributed to the development of the safety recommendations.

- Association of British HealthTech Industries
- Beat Eating disorders
- Breakthrough Type 1 Diabetes UK
- Care Quality Commission
- Community Pharmacy England
- Department of Health and Social Care
- Diabetes UK
- Equality and Human Rights Commission

- Getting It Right First Time
- Health Innovation Network
- manufacturers of insulin pen devices
- Medicines and Healthcare products Regulatory Agency
- Mind
- National Institute for Health and Care Excellence
- NHS England
- Primary Care Diabetes and Obesity Society
- Queen’s Nursing Institute
- Royal College of Psychiatrists
- other experts including academics in mental health and diabetes.